“Look at This Disabled!”

Technologies of the Self and Practices of Freedom among Persons with Physical Disabilities in Zambia

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Tiivistelmä – Referat – Abstract

This Master’s thesis concerns the self-making practices of persons with physical disabilities in Zambia. The thesis is grounded in data gathered across three months of fieldwork conducted mostly in Lusaka, the capital of Zambia. The bulk of these data consists of semi-structured interviews with individuals who were long-time users of mobility aids, namely orthopaedic prostheses and braces, crutches and wheelchairs. The study aims to contribute to broadening the available literature on the subjective experiences of disability, literature that has so far been sparse and disproportionately focused on Europe and North America.

In this study, the task of self-making is approached through Michel Foucault’s concept of ‘technologies of the self’. Dissonant scholarship on ‘practices of freedom’ – technologies of the self that are applied with critical reflection – is examined to construct a workable synthesis. The resultant theoretical construction is then applied to the technologies used by Zambian persons with disabilities to determine whether these may be called practices of freedom. The common assertion in much of the Foucauldian scholarship that practices of freedom lead individuals to practice power in a manner that advances social equality is also interrogated in light of the present study.

The study divides the examined technologies of the self into two groups; those that take as their object the physical being in the world of the individual with disabilities, and those that focus on addressing the narratives – both external and internalised – concerning disability and the individual. Technologies of the former kind examined include the management of one’s apparent level of impairment through the selective use and concealment of assistive devices; the incorporation of one’s mobility aids into the body-image; autonomous movement; and the refusal of help. Technologies in the latter category include accepting disability; challenging preconceptions of inability through example; engaging with others to sensitise them to disability; and self-narration that emphasises capability, mobility, financial stability and universal relevance of impairment.

This thesis argues that dominant local discourse in Zambia still necessitates persons with disabilities to acquire first the capacity to question the prevailing norms surrounding themselves in order to achieve the kind of autonomy exhibited by the informants in the study. In accordance with the constructed theoretical synthesis, this critical awareness qualifies the technologies of the self utilised by the informants as practices of freedom. On the basis of its modest scope, the study gives conditional backing to the idea that practices of freedom create individuals that contribute to processes of social liberation. It is also noted, however, that technologies that may be considered practices of freedom in the context of disability may simultaneously work to reinforce other oppressive power relationships, such as those concerning gender, and that more research is needed on the intersection of disability with other marginalised identities in order to better understand these connections. In the meanwhile, the study encourages researchers to take care to respect the freedom of their subjects to not advance transformative social agendas with their every action.

Avainsanat – Nyckelord – Keywords
disability, mobility aids, narrative techniques, technologies of the self, freedom, liberation, Zambia

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Tiivistelmä – Referat – Abstract

Tämä pro gradu –tutkielma käsittelee liikuntavammaisten henkilöiden identiteettityötä Sambiassa. Tutkielma perustuu aineistoon, joka on kerätty kolmen kuukauden pituisen kenttätyön aikana, enimmäkseen Sambian pääkaupungissa Lusakassa. Merkittävin osa tästä aineistosta muodostuu puolistrukturoiduista haastatteluista. Haastateltavat ovat pitkäaikaisia liikunta-apuvälineiden (proteesien, ortoosien, kainalo- ja kyynärsauvojen sekä pyörätuolien) käyttäjiä. Tutkielman tarkoitus on laajentaa saatavilla olevaa kirjallisuutta vammaisuuden subjektiivisesta kokemuksesta, sillä olemassa oleva kirjallisuus aiheesta on vähäistä eikä edusta riittävässä määrin väestöjä Euroopan ja Pohjois-Amerikan ulkopuolella.

Tutkielma lähestyy identiteettityötä Michel Foucault’n ’itsekäytäntö’ –konseptin (eng. technologies of the self) kautta. Ristiriitaista kirjallisuutta ’vapausharjoitteista’ (eng. practices of freedom) eli sellaisista itsekäytännöistä, jotka toteutetaan kriittisen reflektion jälkeen, käsitellään myös käyttökelpoisen synteesin muodostamiseksi. Syntyvää teoreettista mallia verrataan sambialaisten vammaisten henkilöiden itsekäytäntöihin ja pyritään vastaamaan, voidaanko näitä käytänteitä kutsua vapausharjoitteiksi. Kerätyn aineiston pohjalta tutkitaan myös Foucault’n teksteihin perustuvassa tutkimusperinteessä yleistä väitettä, että vapausharjoitukset johdattelevat yksilöitä yhteiskunnallista tasa-arvoa edistävään vallankäyttöön.

Tarkasteltavat itsekäytännöt jaetaan tutkielmassa kahteen ryhmään; niihin, joiden objektina on vammaisen yksilön fyysinen olemassaolo, ja niihin, jotka pyrkivät kontrolloimaan sekä ulkopuolisia että sisäistettyjä vammaisuutta ja vammaista yksilöä koskevia narratiiveja. Ensimmäisessä ryhmässä tarkasteltaviin käytäntöihin lukeutuvat oman silminnähtävän vammaisuuden tason hallinta apuvälineiden valikoivan käytön ja kätkennän avulla; apuvälineiden sisällyttäminen omaan kehonkuvaan; autonominen liikkuminen; ja avusta kieltäytyminen. Toisessa kategoriassa mainittuihin käytäntöihin kuuluvat vammaisuuden hyväksyminen; vallitsevien ennakkoluulojen haastaminen oman esimerkin avulla; vammaisuutta koskevan tietoisuuden levittäminen toisille; sekä kyvykkyyden, liikkuvuuden, taloudellisen luotettavuuden ja vammaisuuden ennalta-arvaamattoman luonteen korostaminen omissa narratiiveissa.

Tutkielmassa esitetään, että kiitos paikallisen vallitsevan diskurssin, sambialaisten vammaisten henkilöiden on pakko pystyä ensin kyseenalaistamaan heitä koskevat yhteiskunnalliset normit, jotta he voisivat saavuttaa vastaavan autonomian tason, josta tutkielman informantit nauttivat. Tutkielmassa muodostetun teoreettisen synteesin mukaisesti tällainen kriittinen tietoisuus normeista tarkoittaa, että tarkastellut informanttien itsekäytänteet on ymmärrettävä vapausharjoitteiksi. Vaatimattoman laajuutensa valossa tutkielma antaa varovaisen tukensa sille väitteelle, että vapausharjoitteet johtavat yksilöihin, jotka toiminnallaan edesauttavat sosiaalista tasa-arvoistumista. Tutkielmassa myös kuitenkin huomautetaan, että vammaisuuden kontekstissa vapausharjoitteina näyttäytyvät itsekäytännöt saattavat samanaikaisesti lujittaa toisenlaisia epätasaisia valtasuhteita, kuten esimerkiksi sukupuolirooleja. Lisää tutkimusta vammaisuuden ja muiden marginaalisten identiteettien risteyskohtiin peräänkuulutetaan näiden ongelmakohtien ymmärtämiseksi. Lisäksi tutkielmassa kehotetaan tutkijoita kunnioittamaan tutkimuskohteiden vapautta olla tukematta jokaisella teollaan edistyksellisiä yhteiskunnallisia tavoitteita.

Avainsanat – Nyckelord – Keywords
vammaisuus, apuvälineet, identiteettityö, Foucault, itsekäytännöt, vapaus, Sambia

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1. Introduction

The World Health Organisation (WHO) estimated in its *World Report on Disability* (2011) that, based on the best available studies on disability prevalence across the world, some 15.6% to 19.4% of the world population over the age of 15 is living with a disability. With the latest estimates of the world population at the time, this amounted to 785-975 million youth and adults with disabilities in the world – a number comfortably surpassing the population of Europe (741 million, according to Google). The number will no doubt seem unbelievably large to many, as I am sure few of us can claim 15-19 percent of their acquaintances to be persons with disabilities. I certainly cannot, despite counting in my little sister – a person with cerebral palsy – as well as all her school friends, also persons with disabilities. I am, in fact, confident that most people around the world would be able to name more Europeans than persons with disabilities.

Persons with disabilities remain a largely invisible segment of the world population, whether that be in popular culture, politics or academia – both as subjects and objects. While social and cultural anthropology has long been committed to presenting the whole gamut of human experience, in our discipline too, disabilities remain strangely sidelined. That is not to say that there is not a long history of anthropologists examining disabilities – indeed there has been a trickle of disability-focused ethnographies going back at least to the 1930s (Staples & Mehrotra 2016). The problem is that it has remained just that, a trickle, despite a line of successive reviews calling for anthropologists to divert more of their attention to the phenomenon of disabilities (e.g. Ingstad & Whyte 1995; Ginsburg & Rapp 2013).

With the dearth of anthropological studies, disabilities continue to be studied first and foremost through the lenses of medical science, education and development studies, which means disabilities are examined with the express intent of addressing them, whether through individual and medico-technical or social policy means. There remains a wide space, as Whyte wrote over twenty years ago, "between the discursive practice of governments and disability organisations and the subjective experience of an individual living with impairment" (Whyte 1995c: 285). This study on the self-making

of persons with disabilities in Zambia is intended as a small contribution to bridging this wide space.

1.1 Study focus and research questions

This study is based on data collected over three months of ethnographic fieldwork in Zambia; mostly in the state's capital, Lusaka, where I worked as an intern for a Finnish disability-focused NGO. At the focus of the study are persons with physical impairments, all of whom were regular users of more or less conspicuous mobility aids, and the primary data consist of semi-structured biographical interviews with them.

Persons with mobility impairments came to be the subjects of the study due to the original research question, which I discuss in section 3.3. The topic of technologies of the self is, of course, not particular to physical disabilities, even though characteristics specific to physical disabilities do raise certain issues to the fore that might not feature so prominently in the self-making of persons with other types of impairments – movement above all.

Persons with disabilities have been the objects of various kinds of studies, but in this text, I have hoped to portray them as not as passive objects but as acting subjects. Persons with disabilities in Zambia, as elsewhere, still need and deserve society to take action in order to allow them an equal opportunity to live happy and fulfilling lives, but this does not mean that they do not themselves take action to achieve that goal every day, as all of us do. The liberty to pursue happiness is one thing, actually pursuing it another, and it is on this latter aspect that this study is focused.

I approach this topic through the lens of Michel Foucault's concept of *technologies of the self*, cultural self-building practices that work, above all, on the way individuals relate to themselves, striving towards selves that they can be content with (Foucault 1994d). This does not, as it has sometimes been misunderstood, refer to practices that are entirely intellectual – on the contrary, technologies of the self very often involve bodily practice or even political engagement, as we shall see – but to all such practices that involve an effort to transform oneself into a particular kind of subject.

Foucault formed his concept of the technologies of the self mainly by looking at the wealthy male elite of Greek and Roman antiquity, and as such, latter scholars have felt a need to adapt the concept to take into account the ways that these technologies play into, separately from or against systems of oppression when employed by marginalised individuals. They have done so by attempting to define the concept of *practices of freedom*, taken from Foucault's (1994a) work but left incomplete by his early death. I join this long line of speculators on how we might understand the concept, and attempt to apply it in the context of the self-making of Zambian persons with physical impairments.

The primary research question of this study is: *What kinds of technologies of the self do persons with physical disabilities in Zambia employ?* Working with a synthesis of conceptualisations put forward by Foucauldian scholars, I also attempt to answer the question: *To what extent can we consider those technologies practices of freedom?* Given the contested nature of the relationship of liberation – understood here as a lack of oppression – to practices of freedom, I also examine my data to see whether we might find support for a widely proposed idea that practices of freedom contribute to strengthening processes of liberation.

In the second chapter, I introduce my theoretical framework at greater length, delving into Foucault's technologies of the self as well as his thoughts on freedom and liberation. I also introduce the reader to some central models of understanding disabilities as outlined in disability studies (DS), an interdisciplinary field of research that anthropologists have been accused of ignoring (Staples & Mehrotra 2016). In the third chapter I present my data gathering process and the problems encountered along the way. In Chapter 4, I introduce the reader to the situation of persons with disabilities in Zambia, as well as the broad situation of the nation in general.

The chapters thereafter focus on analysing my data in light of the theoretical framework. In Chapter 5, I examine the technologies my informants used to take control of and shape their bodies, and their reasons for shaping them the way they did. In Chapter 6, we look at some of the technologies informants used to shape the discourses concerning themselves, through both action and narration. Chapter 7 examines whether the technologies of the self presented in Chapters 5 and 6 can be said to constitute practices

of freedom, and what the place of these practices might be in broader societal power structures, before wrapping up the study in Chapter 8.

1.2 Notes on terminology

In the successive chapter, I outline a variety of central theoretical concepts that I utilise in this text, both in reference to disabilities specifically, as well as otherwise. It is, however, worthwhile to take a moment first to examine the terminology concerning disabilities and the persons living with them.

While it the offensive nature of terms like *cripple* is widely understood today, much of the terminology remains uncertain for a majority of people. In everyday language, it is perhaps most common to refer to *the disabled*, but disability activism and scholarship consider this formulation as dehumanising and tantamount to equating a person with their impairments (Research & Training Center on Independent Living [RTCIL] 2013). Talking of *disability* or *the disabled* also fails to adequately portray how difficult the concept is to define, and how many different kinds of impairments and different kinds of social inequality it encompasses, which is why disability scholars now prefer to talk of *disabilities* in the plural (Katsui 2012: 3-6). I strive to use the plural in this text, excepting established phrases such as 'disability activism' or 'the social model of disability', or when talking about the disabling circumstances of a particular individual.

The majority of current disability-related literature prefers to refer to *persons with disabilities*. This approach is often called 'person-first language', and is explained as putting the "focus on individuals, not their functional limitations" (RTCIL 2013: 2). Some have suggested employing terms such as *persons with different abilities*, but this has not caught on, as most criticise this kind of language for undermining the very real negative effects of impairments and disabilities (Katsui 2012: 5), while others view them more starkly as "condescending euphemisms" (RTCIL 2013: 3).

A more permanent alternative terminological camp are those who prefer the term *disabled people*. This is also called 'identity-first language', and is most common in disability activism circles, where it is seen as displaying pride in an identity as a person

with disabilities, and an attempt to "reclaim" the term as positive, much as the LGBTI community reclaimed the term *queer* (see Brown 2016). The 8th edition of the influential *Guidelines: How to Write and Report About People with Disabilities* (RTCIL 2013) acknowledges the existence of this preference, but recommends that nondisabled persons utilise person-first language as standard, as the most objective and respectful option. As is discussed on a few occasions in this text, not all persons with disabilities see disability as a primary factor in their identities. In this study, I therefore use the term *persons with disabilities*, or *PWDs* for short. The Guidelines also suggest that the preferable, non-value-loaded term of contrast to persons with disabilities is *nondisabled people* or *persons without disabilities* (ibid.). I utilise the former in this text, as this is in my opinion easier for the reader to distinguish from *persons with disabilities*.

In everyday Zambian English usage, using the term *disabled* is most common, and *able-bodied* is usually its opposite. I have, of course, left the language of my informants as is in quotations. Notably, the word *disabled* can be utilised both as an adjective and as a noun in Zambia, i.e. "I became disabled when I was four years old" and "I became *a* Disabled when I was four years old" would both be equally valid formulations. In this text, uses of the term as a noun will be capitalised for clarity.

I ask the reader to bear in mind that, while many of the challenges and prejudices faced by persons with various kinds of disabilities in Zambia may be the same – as may the technologies they can use to combat them – this study is focused on persons with physical mobility impairments, and cannot claim to represent the lives of all manner of PWDs in the country. For the sake of brevity, I use the term *persons with disabilities,* or rather *PWDs,* throughout this text, but most commonly, I refer by this to persons with mobility impairments. I trust the reader will be able to define the contexts where this is not the case.

2. Theoretical framework

2.1 The many models of understanding disability

In their article on the state of anthropological research into disabilities, Staples and Mehrotra (2016: 35,37) note that (the few) anthropologists writing on disabilities have rarely engaged with the broad interdisciplinary field of disability studies, more likely out of ignorance of the field rather than conscious dismissal. While they also find some reasons why anthropologists might be reluctant to get involved with DS – to be examined below – they nonetheless conclude that anthropological studies of disabilities would be unwise to dismiss offhand the terminology and theories of disability studies, which have been formed over more time and through greater debate (ibid.). Therefore, it is an appropriate response for us to begin this theoretical chapter by looking at certain central concepts in disability studies, as well as looking at the field itself.

Disability studies is commonly considered to have its roots in the emergent disability activism of the US and the UK in the 1960s and 1970s. As described by Vehmas (2005: 109-111), growing disillusionment amongst PWDs with the medical model of disability which had dominated policy, rehabilitation and special education led to the formation of various organisations of persons with disabilities demanding autonomy and independence. In their efforts these organisations drew much of their inspiration from other contemporary movements demanding social justice, such as those focused on inequalities of race, gender or sexuality (Staples & Mehrotra 2016: 39).

Following these antecedents, the view put forth by the disability movement was that, like darker skin or the feminine gender, disability did not in and of itself have negative effects, but rather it was the organisation of society that led to the marginalisation of persons with disabilities. Persons with disabilities, then, were to be considered another oppressed minority group.

This position was most famously crystallised by the British organisation Union of the Physically Impaired Against Segregation (UPIAS) in their heavily quoted (e.g. Goodley & Swartz 2016; Vehmas 2005) 1975 paper *Fundamental Principles of Disability*. In it was

outlined the dichotomy of terms that would take a central place in disability studies, that of *impairment* and *disability*:

> "Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression." (UPIAS 1975: 14.)

This dichotomy is the basis of the *social model of disability*, also termed the materialist view on disability, due to its close association with Marxist historical materialism (Vehmas 2005: 120). Experiences of disability, in this view, are caused by physical barriers to participation for PWDs in a society that was not built with them in mind, by negative attitudes that serve to marginalise those with disabilities, and by institutions such as care homes and special education, which isolate PWDs from society at large (ibid.: 120-121).

As such, experiences of disability are, of course, shaped by the particular society in question, with local differences arising from particular histories and material circumstances. The current form taken by disabilities in the West, proponents of this view assert, took shape in the aftermath of the Industrial Revolution, as factory conditions demanded reliable, uniform capabilities from workers. Persons with disabilities were not able to meet these standards, and, being unable to contribute, started constituting a problem for society, which from the beginning of the 19th century onward, began to be addressed through isolating PWDs in special institutions, where medical means were employed in the attempt to "normalise" their faulty individual bodies and/or minds. (Vehmas 2005: 120-121.) Failing a cure, at least the scale of the problem posed by PWDs to society might be addressed through sterilisation and euthanasia (Goodley & Swartz 2016: 70).

It is therefore no surprise that the social model of disability has been constructed very much in opposition to *the medical model of disability* employed in treatment, rehabilitation and special education (Goodley & Swartz 2016: 70). According to critiques from

disability studies, the medical view has concentrated solely on disabilities as problems located in the individual who deviates from the "normal", to be diagnosed according to universal definitions and then addressed by methods which seek to bring the individual (back) up to the level of "normal" functioning (Vehmas 2005: 111-112).

While more extreme practices like sterilisation may have fallen out of vogue, the medical model is still seen as problematic for several reasons. Firstly, by locating the problem in and seeking to treat the individual, the model ignores and naturalises the conditions in society that work to disable PWDs (Goodley & Swartz 2016: 70). As a well-worn example goes, in a building with no stairs but only ramps and elevators a wheelchair-user is equal to those capable of walking (Vehmas 2005: 124). Instead of highlighting the need for ramps and elevators, however, the medical model would rather attempt to get wheelchair-users walking. In the words of Goodley and Swartz, "presenting the disadvantage of disability as the consequence of a 'naturalised impairment' or 'biological flaw' lets exclusionary society off the hook" (Goodley & Swartz 2016: 71).

The medical model is also seen as abrogating the agency of PWDs to the benefit of medical professionals and state caretakers. While PWDs themselves rarely benefit from knowing the precise terminology concerning their impairment, diagnosis instead serves to delegitimise their authority to affect their own treatment – building for the PWD what some have called a *pathological identity* – as trained professionals are considered to understand the condition of the individual with the impairment better than the individual themselves. This means it is the professionals who have the final say over procedures and processes. (Vehmas 2005: 91-92, 100, 114.)

Not only is this pathological identity present in encounters with various professionals and authorities, but it often comes to colour the self-image of the individuals themselves. In the terms of classical sociology, the individual with the disability assumes *the sick role* – they are "excused" from much of the normal obligations of everyday life, but must in return devote themselves to getting better – i.e. follow the orders of medical professionals and other caretakers. "This expectation", as Murphy explains, "mandates the proper role of the sick as one of passivity" (Murphy 1990: 19). In this way the medical model can embed a deep resignation of personal agency in the minds of persons with

disabilities. This danger features prominently in various disability memoirs (e.g. Murphy 1990; Saraste 1996), and is also related to the issue of family overprotectiveness which threatens to smother the subjectivity of PWDs, as is discussed in Chapters 4 and 5.

Now, in the history of so-called Western culture, the medical model itself succeeded a *moral approach*, which is seen to have been the dominant way of understanding disabilities in antiquity and the Middle Ages. In such a view – an explanatory model above all – impairments have a supernatural cause, often reflecting the moral being of the individual. Often this meant understanding disabilities as divine retribution for the individual's bad deeds or ill will, or being possessed by evil spirits, although more positive explanations existed as well, including seeing PWDs as vessels of a sort put on Earth by God, so that through them good Christians might practise the virtue of charity (Vehmas 2005: 41-44). However, both positive and negative attributions located disability squarely in the individual, thus promoting an *individual model of disability* just as much as the medical model, and serving to limit the personhood of PWDs (Goodley & Swartz 2016: 70-71). While the medical model has vastly overshadowed the moral understanding of disability, less conscious vestiges of the latter still remain (Murphy 1990: 90-94).

In recent years, scientific circles outside disability studies have started to take notice of the criticism levelled at the medical model, and attempts have been made to combine aspects of both social and medical models. Perhaps most importantly, the *International Classification of Functioning, Disability and Health* published by the World Health Organisation, which aims to be a universally applicable tool for professionals assessing the degree of disability, defines disability as "an umbrella term for impairments, activity limitations or participation restrictions" (WHO 2001: 3). The same three-pronged definition is adopted by the WHO's *World Report on Disability*, which terms the approach a "bio-psycho-social model" (WHO & World Bank 2011: 4). As such, this model seeks to incorporate biological impairment, individual needs and desires ("activity limitations") and challenges posed by particular local realities ("participation restrictions").

While the *World Report on Disability* has been lauded for devoting a greater share of attention to disabilities in the Global South (Goodley & Swartz 2016: 73-74) and bringing visibility to disability issues in general (Grech 2016: 5-6), it has also received some limited criticism. Prominent theorists of the materialist view on disability have questioned the report's positivist bent in studying disabilities as a phenomenon, thus invalidating more politicised and subjective studies, and have accused the text of harbouring hidden capitalist agendas (the report is coproduced by the World Bank, after all; see Goodley & Swartz 2016: 74). Related to the former accusation of positivist leanings, of course, is a broader discussion on whether such universalising descriptors for disability can be constructed at all, given the wildly varying local conceptions of the term, or its closest local equivalents (see Ginsburg & Rapp 2013: 57-59; Whyte & Ingstad 1995: 5-7).

While the social model continues to be central to disability studies and its proponents have undoubtedly managed to raise consciousness of the failings of the medical model, the social model has also been questioned, even from within disability studies itself. For one, like its predecessors in Marxist historiography, the social model has faced criticisms of material determinism: overlooking cultural aspects of disabilities in favour of social organisation and economic factors. This has been especially relevant in studies outside the Western cultural sphere, where said factors may be radically different, but also among minorities in the West. Indeed the harshest critics have gone as far as to accuse the social model of being based on the white American or European male as the image of human nature, and accuse disability studies based on the social model of thus pushing the agenda of the white, Western (possibly academic) male (Goodley & Swartz 2016: 72-73; Vehmas 2005: 145). Critics argue that this has led to certain topics which might be especially important to the white Western male, such as salaried work, to feature overly prominently in writings on disabilities (Goodley & Swartz 2016: 72-73).

While it may have been constructed explicitly in opposition to the medical view on disabilities, the social model has also been criticised for accepting too readily many of the dichotomies that underlie the medical model. For example, with its talk of "impairments", critics say, the social model does not do enough to question the objective existence of such impairments. This is especially questionable in regards to intellectual

disabilities, where talk of impairments might be taken to imply that there does indeed exist an objective normality, which individuals with learning disabilities or Attention Deficit Disorder, for example, are incapable of achieving thanks to some biological fault. This obscures the fact that these delineations of what constitutes "normal" functioning or a "normal body" are socially constructed concepts that vary across cultural settings. (Vehmas 2005: 122-123, 141-142.)

An alternative model for understanding disability as a phenomenon that seeks to better portray its cultural specificities is *the social constructionist model*, which emphasises the importance of cultural factors like language and values on local experiences of disability. Proponents of this view might argue that the material realities of any given society are likewise grounded in and an aspect of culture, as culture guides the way the environment is shaped by society. (Vehmas 2005: 121-124.) The division between the social and the social constructionist model is, however, crude and largely conceptual as Vehmas notes, since most studies in DS do consider both material and cultural factors, even if differences in emphasis exist (Vehmas 2005: 119).

Furthermore, both the social model and the social constructionist model have come under fire for sidelining individual impairments. In campaigning against medical conceptions of disability, disability studies has been accused of ignoring the unique and personal problems that missing limbs, pain and fear of death might pose to individuals regardless of social setting. Some PWDs can and do feel that it is primarily their impairments and not social organisation that hinders them in their lives. (Goodley & Swartz 2016: 74; Vehmas 2005: 143-145.)

Disability studies and the social model especially have also been criticised for pushing too harsh a dichotomy between persons with disabilities and those without. With its steadfastly political nature, disability studies is sometimes seen as trampling over the individuality of PWDs, claiming to speak for all of them (see *white American/European male academic*, above) and asking all PWDs to identify as such, while in reality many of them do not, instead seeing themselves primarily through other categories, such as gender or ethnicity (Vehmas 2005: 143-145). As such, disability studies has often failed

to connect with other transformative and political perspectives (Goodley & Swartz 2016: 73).

The separate theoretical viewpoints put forward in disability studies have no doubt done much to advance a more complex view of disabilities. All of them also have undeniable faults if too strictly adhered to. Like most current studies, then, I attempt not to over-emphasise any particular aspect of disabilities – material, cultural, or individual – at the expense of others. Given, however, that the focus of my study is on *individual and transformative* practices, for this I turn instead to a theorist from outside of the field of disability studies for my main theoretical framework.

2.2 Technologies of the self

The French philosopher Michel Foucault, widely acknowledged to be one of the most influential thinkers of the previous century, is best known for his theories of power and social control. Foucault's major works were historical examinations – which he termed "genealogies" – of various institutions and concepts of importance in modern Western society, such as psychiatry (Foucault 1973), the prison (1977) and the concept of sexuality (1980, 1986a+b).

One of the most important theoretical contributions Foucault developed in these works was the understanding of ´power´ not as a force, a coercion applied by the powerful on the powerless, but as an omnipresent facet of all human relations: Wherever two people are involved in a relationship, they will always attempt to some extent to control the conduct of the other. Foucault himself in fact stated that if he ever used the term ´power´ he used it as a shorthand for ´relations of power'. (Foucault 1994a: 291-292.)

On a wider scale, then, the concept of power refers to "a general matrix of force relations at a given time, in a given society" (Dreyfus & Rabinow 1982: 186). The fact that power emanates from the interaction of individuals, in turn, means that power is not restricted to coercive institutions, as it is often imagined (ibid.: 185). Indeed, Foucault's historical analyses of Western modernity aimed to show how modern societal control happens in more subtle ways. He argued that the defining form of social control in the modern age

was *biopower*, the utilisation of scientific technologies for political means. Biopower made scientific categories like population and species into matters of political attention, and utilised new *disciplinary technologies* developed and employed across various locations such as medicine, the military and disciplinary institutions to produce docile and productive "normal" citizens, who would internalise these disciplinary controls and police themselves. (ibid.: 133-136.) One might note a distinct overlap between Foucault's thinking about biopower, discipline and docility and the view from disability studies on the pacifying and normalising medical model of disability.

While ideas of discipline and biopower have proven highly influential, lesser attention has been given to Foucault's latter thinking, focusing not on power over others but power over the self. It seems that toward the end of his life Foucault himself expressed some regret that he had devoted so much of his time to examinations of social control:

> "Perhaps I've insisted too much on the technology of domination and power. I am more and more interested in the interaction between oneself and others and in the technologies of individual domination, in the mode of action that an individual exercises upon himself by means of the *technologies of the self*." (Foucault 1994d: 225, emphasis added.)

Ostensibly his interest in self-cultivation grew as he was writing the first volume of *The History of Sexuality* (Foucault 1980). Originally meant to detail the development of a separate concept of ´sexuality´ as an aspect of biopower, Foucault became aware as he delved into ancient Greek and Roman texts that sex was but one (and by no means the major) topic in a wide range of prescriptions on how one should seek to conduct oneself. It was these prescriptions, these ´technologies of the self´, and their historical development from antiquity to the early Middle Ages that drew his attention in volumes two and three. (Foucault 1994b: 253-255.)

As per Foucault's most widely quoted formulation, technologies of the self "permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1994d: 225). Whereas the technologies of power

examined in the major part of Foucault's work seek to *objectify* others, technologies of the self serve to *subjectify* oneself, to turn one into a particular kind of subject (Markula 2003). This makes them a particularly appealing theoretical concept for studies such as this that focus on the self-making of individuals.

Historical and local factors help to shape the different types of relationships individuals might have to themselves, and it is the field of relations to the self that Foucault – borrowing from the Greeks (Foucault 199d: 286) – terms *ethics*. It is worth clarifying that for Foucault, ethics is separate from (though related to) morals, the latter of which he describes as the code that delineates which acts are acceptable and which are not (Foucault 1994b: 263). Ethics, meanwhile, "determines how the individual is supposed to constitute himself as a moral subject of his own actions" (ibid.). Particular situations thus may present us with moral quandaries – questions of right and wrong – but ethics itself is irreducible to individual situations (Sidnell 2017: 14).

Foucault outlined four historically and culturally variable dimensions of ethics, all of which I will come back to during the course of this study: First, there is the *ethical substance*, the aspect of ourselves that we are meant to control and transform for us to be able to be our own best versions; the material of ethical work. Some examples of this include pleasure and desire for the ancient Greeks, "the flesh" in medieval Christianity, and in Kantian ethics, our intentions. (Foucault 1994b: 263-264.) Second, there is the *mode of subjectivation*, "the way in which people are invited or incited to recognize their moral obligations" (Foucault 1994b: 264), i.e. why is a particular way to live the right way to live? Perhaps it is decreed by divine law, or perhaps it is, instead, the "rational" path (ibid.). As I argue in section 5.3, human rights might also be constituted as a mode of subjectivation.

Third are the technologies of the self, the tools of ethical work, which Foucault also called the self-forming activity [*practique de soi*] (Foucault 1994b: 265). As he outlined in his latter works, for the Ancient Greeks and Romans the array of available technologies encompassed such variable practices as physical exercise, dietary regimen, exercises of abstinence, interpretation of dreams and daily, report-like accounting of one's activities in a diary or in correspondence (Foucault 1986a+b; 1994d). An account of such

technologies in use by PWDs in Zambia is the primary goal of this study. Lastly, there was the aspect of *telos*, the goal of ethical work, "the kind of being to being to which we aspire" (Foucault 1994b: 265).

Foucault suggested that in the course of history and across cultures, the transformation of morals happens very, very slowly if at all, but it is in variations in the four aspects of ethics that differences can be more readily observed. This – as he later claimed – was what he had tried to show in the second volume of *The History of Sexuality*, *The Use of Pleasure*. (Foucault 1994b: 265-266, 268.) To put it in very general terms, Foucault maintained that from the times and teachings of Plato to Christianity in the early Middle Ages, the moral codes of sexual conduct for men change very little: one should be faithful to one's wife, avoid sexual relations with boys, and avoid excessive sexual activity in general. What changes is why one should try to follow these moral obligations. Between classical Greece and early Christianity, for example, the goal (*telos*) shifts from mastering the self in order to be able to master others to attaining the purity that will grant a place in Heaven; between the Stoics and early Christians the mode of subjectivation goes from the compulsion to be a rational being to following divinely decreed law. The techniques utilised in the pursuit of these goals, of course, also changed over time. (Foucault 1994b: 265-269.)

"Freedom is the ontological condition of ethics", Foucault posited (1994a: 284), and there is by all accounts a tight link in his thinking between ethics and freedom. This link has been conceptualised in many different ways, but Sidnell interprets the core of this idea to be that that "ethics as the relation of the one to itself implies a certain degree of active engagement" (Sidnell 2017: 13), that ethical cultivation of the relationship to the self is a form of labour "one *chooses* to actively pursue" (ibid.; emphasis in original).

For there to be any real choice there must also be an awareness of other options and true reflection on those options. This is perhaps the most agreed-upon aspect of ethical practice among Foucauldian scholars, though again the words they use vary.

> "Only critical self-reflection can result in a change to one's condition. To be able to think differently creates an opportunity to question the limitations of one's freedom instead of merely coping with one's situation. The critically self-aware

> individual constantly questions what is seemingly "natural" and inevitable in one's identity and, as a result, creates an identity of his or her own." (Markula 2004: 308.)

This relationship between ethics and freedom also seems to me to be the point from which a lot of theoretical discord between Foucauldian scholars originates. Foucault unfortunately passed away before he could truly elaborate on this question and construct a clearly defined theoretical framework, leaving behind only scattered quotes and the interview (conducted five months before his death) published by the name *The Ethics of the Concern of the Self as a Practice of Freedom* (1994a; also translated as *The Ethics of the Care of The Self* - -). This sparsity of original sources has left successive generations of scholars in a state of even greater disunity on this topic than on those topics of which Foucault wrote in abundance. My interpretation here is founded mainly on formulations put forward in the texts by Markula on women's mindful fitness (2004), Sidnell on yoga (2017) and Valdez on the *niqab*, the full veil used by some Muslim women, in France (2016), and while the terminology and details across them differ, however, I believe a workable synthesis can be constructed.

2.3 Critical awareness, freedom and liberation

So freedom is the condition of ethics and ethical practice is a form of labour that one chooses to pursue, but how do we know an action is truly, actively *chosen*? What does all of this really mean, for the individual and for the society? And how does all of this relate to technologies of the self? As noted above, one might well say that the jury is still out on these questions, but with a good long look at the dissonant literature, a framework is beginning to emerge. In order to examine whether the self-making practices of Zambian PWDs can be said to be free from oppressive norms, and whether they contribute to the building of a more equal discourse on disabilities, we will need to tease out this framework.

Pirkko Markula (2003: 304) has argued that Foucault's definition of technologies of the self has been wrongly taken by many to mean that they constitute "resistant" practices, practices that rebel against dominant discourses. While they are transformative on an

individual level, however, the technologies do not necessarily contain any element of resistance to dominant social norms. Indeed in his major works outlining the concept of technologies of the self, volumes 2 and 3 of *The History of Sexuality* (1986a+b), as well as the seminar *Technologies of the Self* (1994d), the practices Foucault examines seem more to reinforce dominant discourses, such bodily and masculine ideals. In many cases, as Markula (2003: 89-91) pointed out concerning female athletes' dieting practices, technologies of the self may appear more to be coping mechanisms that allow individuals to feel better about their compliance to dominant discourses, and there are certainly grounds for arguing that some of the practices examined in this study may also amount to coping mechanisms, as we shall see.

As such, some have instead criticised the concept of technologies of the self for offering no route towards meaningful social change. For example, Guthrie and Castelnuovo (2001) found Foucault's conception of resistance to be too individualistic as well as intellectual, and thus unable to account for the power of physical and collective practices. Markula, however, has pointed out the authors' limited engagement with Foucauldian concepts (2003: 93), and I feel inclined to concur that their interpretation stems, at least partly, from a limited reading of his works.

Guthrie and Castelnuovo assert that for Foucault, "resistance as freedom must remain an individual act, because if the potentially liberating practice becomes part of a group dynamic, the possibility of a new, yet equally confining, discourse is created" (2001: 7). This phrasing seems to suggest a conception of any power relations as oppressive, in accordance with a "freedom as nondomination" view (Valdez 2016). For Foucault, however, power is present in any relationship, and in any relationship both sides may exercise some degree of power over the other, however small. As an example he provides the extremely one-sided marriages common in the West in the 18th and 19th centuries, as even here women could "deceive their husbands, pilfer money from them, refuse them sex" (Foucault 1994a: 292). In fact, Foucault contended that the existence of freedom, even in the tiniest amount, is necessary for there to be something to exercise power over (ibid.; Foucault 1982: 221-222).

That does not mean that Foucault did not recognise the existence of totally unbalanced power relations, which he called *states of domination*. He defined these as situations where "power relations are fixed in such a way that they are perpetually asymmetrical and allow an extremely limited margin of freedom" (Foucault 1994a: 292). The abovementioned marital relationship of a few centuries back was also an example of a state of domination: It is incorrect to assert that the wife wielded *no* power, but what few tactics she could employ "never succeeded in reversing the situation" (ibid.).

So it seems to me that Guthrie and Castelnuovo make the mistake of thinking that, for Foucault, the creation of new power relations through collective resistance automatically meant the formation of new oppressive relationships. Their text conveys a view of freedom as a lack of forces seeking to control the individual, while in Foucault's view, such a state would not be possible for anyone who wished to live in a society and engage in any kind of human relationships (see Valdez 2016). Instead, power relations are inevitable, and in and of themselves neither positive nor negative. The point "is not that everything is bad, but that everything is dangerous" (Foucault 1994b: 256) – collective resistance *can* turn into the new oppression, but it doesn't *have to.*

If not by severing power relations, then how do individuals achieve freedom, and how can their collective practices avoid sliding into oppression? Due to his conceptualisation of power, Foucault wanted to avoid defining freedom as a state (Valdez 2016: 20-22). After all, if power is present in every relationship, then the only way to sustain a state of no subjection to power would be to avoid any and all human relations. Instead, Foucault consistently talks of *practices of freedom*, an expression which conveys a constant need for the individual to work on the ethical self and remain mindful of the influence of external forces (ibid.: 22). Freedom is to be found in – and constantly reaffirmed by – practice.

The term ´practices of freedom´ has, however, been used by later writers in wildly varying ways. Some feminist scholars such as Thorpe (2013) and to some extent Markula (2004; her usage of the term is less clearly defined) have utilised 'practices of freedom' to refer to those technologies of the self that contest dominant discourses, such as presenting the female self in the media in traditionally non-feminine ways (Thorpe 2013). In my view, however, taking the term ´practices of freedom´ to mean only such

practices that go against the grain of dominant discourse undermines the agency of those individuals who, equipped with critical awareness, still choose for whatever reason to shape their lives in the mould preferred by dominant discourses.

Suggesting that those with the means to engage in transgressive self-forming activities choosing to forgo such practices is necessarily a result of a lack of critical awareness, as for example Thorpe (2013: 222-223) does, smacks of the belief in "an inborn aspiration for freedom understood as the assertion of autonomy in ways that challenge social norms rather than upholds them" (Mahmood 2012, as cited in Valdez 2016: 24) – a belief which Foucault himself was much opposed to (Foucault 1994a: 282-283). Such a definition of practices of freedom risks criticisms of an "inability [] to conceive of forms of human flourishing outside the confines of a liberal progressive imaginary" (Mahmood 2012, as cited in Valdez 2016: 24), such as have been levelled at feminist theory and disability studies as well, as noted above. (In fairness, Thorpe (2013: 224) does note that the image of femininity advanced by her female snowboarders doesn't serve the interests of all women, such as elders and women of colour.) As I argue in the concluding chapter of this study, texts loaded by such a view on freedom can also add to a heavy feeling of obligation felt by some members of disadvantaged groups to constantly evaluate their every action in the context of challenging dominant discourses.

A highly useful distinction is made[1] in *The Ethics of the Concern of the Self as a Practice of Freedom* between freedom, the positive capacity of the individual to exercise power over their own being, and liberty, the absence of dominating forces that would limit said capacity (Foucault 1994a: 282-284). Liberty, in other words, is understood as the state of nondomination that is often the stated endgame of activist theorists such as Guthrie and Castelnuovo as well as Thorpe, but one that, while being a precondition of practicing freedom, does not by itself present the necessary conditions for living a life of happiness and fulfilment. Thus defined, looking at *practices of freedom* and *processes of liberation* separately allows us to respect the variable ways in which individuals may choose to

[1] It is to be noted that I am working with a translation and cannot say whether this distinction is in the original text or has been made in the process of translation. This does not, however, reduce the usefulness of this division.

live their lives, without ignoring their place in the "macro structures of oppression" (Guthrie & Castelnuovo 2001: 97), as has often been the critique of Foucauldian theory.

In this text I therefore define practices of freedom in line with Valdez (2016) as being any technologies of the self that are employed with critical reflection, as opposed to those that are imposed by external norms and/or adopted uncritically. The defining criteria here is thus neither the action undertaken (such as veiling vs. unveiling; or, for an example from this text, participating in common PWD activities or not) nor its place in external discourses (transgressive or conformist), but the consideration and intent with which it is performed.

Using this definition it also becomes possible to conceive of conformity to external instruction also as a practice of freedom, granted that the motivation to do so is internal and grounded in real self-reflection. Valdez (2016), for example, explains that many French Muslim women see veiling as a voluntary act of submission to God and a central practice of training to be a more pious self, rather than them simply veiling due to social pressures. Sidnell (2017), meanwhile, talks of willing submission to the guru as central to the ethical practice of yoga. Indeed, Valdez emphasises the important distinction between docility as "the malleability required of someone in order for her to be instructed in a particular skill or knowledge," and docility as "the unreflective adoption of imposed norms and constraints characteristic of discipline" (Valdez 2016: 20).

It is undeniable that the actions of individuals do influence societal discourse in ways that are not necessarily dependent on the intent of the individuals undertaking them. As such, it is not inconceivable that practices of freedom might also contribute to entrenching social imbalances of power. However, several scholars (Markula 2004; Schneider 2012; Thorpe 2013) have resurrected the classical Greek notion that proper ethical care of the self *will* result in the better and more just administration of one's power over others – "practices of freedom aim for a delicate practice of liberty" (Markula 2004: 307). These are often the same scholars that conceptualise practises of freedom as transgressive practices, a definition which I, as noted, avoid here. Despite me employing the terminology differently, however, the idea is still worth examining. Foucault himself was more cautious on the subject, and I feel many writers have too boldly interpreted

his statements about Greek ethics to be universal statements about ethics (e.g. Schneider 2012: 414), but it is still not entirely farfetched to conclude that this was, to some extent at least, Foucault's view as well (Foucault 1994b: 256-262).

We arrive, therefore, at the following theoretical formulation, which I will utilise in this study: ETHICAL CARE OF THE SELF is the project that is pursued through PRACTICES OF FREEDOM – distinguishable from other TECHNOLOGIES OF THE SELF by the presence of critical awareness – which leads individuals to exercise power responsibly and partake in practices that bring into question dominant discourses, thus reinforcing PROCESSES OF LIBERATION. The plausibility of the last part of this formulation, the connection of practices of freedom and liberation, will be one of the things interrogated in at length in Chapter 7.

3. Data and Methodology

3.1 Data gathering process

The data for this study were collected over 11 weeks of fieldwork in Zambia between June and September 2017. The data collection took place in the capital, Lusaka, with the addition of one trip southward to Livingstone to meet Musola Kaseketi, a prominent Zambian disability activist and one of the interviewed informants in this study.

During this time, I worked as an intern for the Finnish NGO the Abilis Foundation, which channels funding to projects in so-called developing countries that are planned and implemented by PWD-majority groups of locals. My task at the Foundation was to collect data on the long-term impact of funded projects that had since ended. As such, I spent a great deal of my time in Lusaka visiting and trying to get in touch with these groups that had received Abilis funding. Some of the groups and projects I spent more time with included APTERS (Appropriate Paper Technology), an organisation founded in 1990 that produces affordable mobility aids for children with disabilities out of recycled paper and cardboard, as well as employing adult PWDs; Disacare Wheelchair Centre, also founded in the 1990s and with a PWD-majority workforce, which produces wheelchairs and other mobility aids designed for the local environment; and Action for Self-Reliant Disabled, a collective of PWDs seeking to employ themselves and potentially others through agricultural work.

Other locales central to my study were the prosthetics and orthotics clinics in the city. As I was not able to contact the University Teaching Hospital (UTH) in Lusaka – no doubt the largest single supplier of assistive devices in the country – from Finland, I was not able to get the necessary permissions to recruit interviewees at the hospital's clinic beforehand, and decided against spending my limited time on acquiring the permits on-site. Instead, I spent more time at the NGO-run St. John Paul II Orthopaedic Mission Hospital (formerly the Zambian-Italian Orthopaedic Hospital, and still known by many in Lusaka as "the Italian hospital"), where the hospital administration was quicker to

allow me contact with their patients. However, I did visit the UTH on three occasions as well, to talk with staff and observe the operation of the clinic.

As a third focal point, I visited the weekly shared training session of Lusaka's wheelchair basketball teams at the Olympic Youth Development Stadium (OYDC) three times. While the game is played in a wheelchair, the teams consisted of players with various mobility impairments, and the wheelchairs used in-game were property of the teams. The players ranged in age from their teens to their late middle ages, were of both genders and came to the stadium in the North of the city from all around town.

The primary data of this study, interviews with PWDs recruited from these various sites, are detailed below. In addition to this, supplementary data were gathered in the form of observational notes at all the above-mentioned sites and in informal conversations with locals during the entirety of my stay. I also kept a detailed diary of the fieldwork period, writing down the events of each day before going to bed.

3.2 Interview material

The backbone of my data consists of 14 semi-structured interviews with a total of 16 informants[2] (see Table 1), recorded with the interviewees' permission and selectively transcribed at a later date. The interviews range in length from some 40 to 80 minutes. Central topics of these interviews included the informants' life stories, their relationships to their assistive devices, and the societal status of persons with disabilities in Zambia. The direct quotations of informants in this text are from these interviews unless otherwise stated.

Of the 16 interviewees, five were met on Abilis-related visits; four were patients at the Mission Hospital. Another four were recruited at the basketball practices, and a further four through snowballing, i.e. through other contacts. In recruiting interviewees, I strove

[2] One interview was left out of this study as my research focus shifted (see section 3.3). Since the informant, an older male, had been amputated only six months prior and was still getting used to his new prosthesis, I figured this made his case markedly different from my other interviewees who had been living with their impairments for many years. While contrasting the technologies employed by those with recently acquired impairments is a topic worthy of study (Guthrie and Castelnuovo (2001) examined this to some extent), a reference group of one is hardly sufficient for such an examination.

TABLE 1.
Interviewees in the study

Name	Age	Gender	Assistive devices	Cause of impairments	Age at Onset of Disability	Disability age	Employment status	Relationship status (+ Housing status, if not household head)
Andrew Tembo[1]	28	M	Wheelchair	Spinal chord injury sustained in traffic	21	7	Student (clothing design)	Dating nondisabled girl (living with parents)
Beatrice*	38	F	Brace+Crutch	Polio	2	36	Lab technician; Entrepreneur (tailoring)	Divorced w/ 2 children
David Miti	50	M	Wheelchair	Gas gangrene requiring amputation	34	16	Project-based work (repairing assistive devices)	Married w/ 2 children, wife able-bodied
David Mukwasa	50 (approx.)	M	Wheelchair	Polio	3	47 (approx.)	Disacare board member; Entrepreneur (imports)	Married with children, wife unknown
Derrick Tembo[1]	37	M	Crutches	Polio	2	35	Project-based work (repairing assistive devices)	4 children from 3 marriages, current wife PWD
Grace*	39	F	Crutches	Other disease	(17)	(22)	NGO officer	Married, husband PWD
Harriet Chali	34	F	Wheelchair	Polio	7	27	Unemployed	Separated w/ 1 child (living with sister and her children)
Iris*	24	F	Leg orthoprosthesis	Congenital	0	24	Orthopaedic technician	Single (living with sister)
Jethro Daka	50	M	Wheelchair	Polio	6	44	Car salesman in collective	Single (living with brother's family)
Kenny Mubuyaeta	49	M	Brace(+Cane)	Polio	5	44	Disacare executive	Married w/ 5 children, wife able-bodied
Mary Mamba	35	F	Leg prosthesis	Traffic accident requiring amputation	12	23	Piece work (domestic)	Single (living alone)
Moses Chishimba	42	M	Crutches	Polio	3	39	Self-employed; agricultural collective	Single (living with siblings)
Musola Kaseketi	49	F	Crutches	Medical error	0	49	Filmmaker; Activist	Single (living alone)
Richard Lubanza	27	M	Crutches	Polio	0	27	Self-employed; agricultural collective	Dating able-bodied girl (living with parents)
Roland*	44	M	Leg prosthesis	Traffic accident requiring amputation	18	26	Self-employed vendor	Married w/ 3 children, wife able-bodied
Seawell Mboshi	49	M	Wheelchair (+prosthesis)	Burns requiring amputation	27	22	Disacare employee; Para-athlete	Married w/ 7 children, wife able-bodied

[1] No relation

for the widest possible representation of gender, age and type of mobility aids used – this last criterion primarily because of my original research question, discussed below. Male informants turned out to be easier to find, and the data are skewed in their favour despite my best efforts, with 10 male and 6 female interviewees. I suspect a combination of factors – where a more mobile local male role meant I simply met more men than women, and my own gender made it easier for men to accept requests for interviews – is responsible for this.

Regarding the distribution of assistive devices, at the moment of interviewing 4 informants were using a prosthetic leg, 6 were wheelchair users and 7 used crutches, some in conjunction with lower-limb and/or spinal orthoses (locally called braces or calipers), though one informant used a crutch or cane only occasionally. Due to my efforts to obtain an even distribution of this kind, the data do not reflect the distribution of mobility aids in Lusaka or Zambia generally. Age-wise, I was unable to completely avoid my data reflecting the higher prevalence of impairments among older segments of the population, with three informants in their twenties, seven between 30 to 45 years and six over the age of 45 (Zambia's life expectancy at birth currently being around 53 years [Central Intelligence Agency 2018]).

The primary cause of disability among my interviewees was childhood polio, accounting for half of the cases, which is likely to reflect the reality of physical disabilities in Zambia in general (although this is only conjecture, as no data exist on the causes of physical disabilities specifically; for a statistical overview of the causes of disabilities in Zambia generally, see segment 4.2). Four interviewees had been impaired due to accidents, three traffic related and one a house fire. Two more cases were due to other diseases and one due to a medical error, with only one case of congenital disability. Due to the low age of onset for most cases, the disability age – the time one has lived with an impairment – of most of my interviewees was rather high: the disability age of one informant was seven years, and another's 16 years, but for the rest of my informants their disability ages ranged between two to five decades.

It is to be noted that the informants in this study were generally better off than their average PWD peers, if not on the scale of Lusaka then at least on the scale of Zambia in

general. While precise statistical data are not available to back up this claim, I am convinced that the simple fact of their having access to assistive devices is proof of this. Anecdotal evidence from both PWDs themselves and workers in the field attests to the fact that there is a far greater number of persons without the means to acquire their own assistive devices in the country than can be addressed by NGOs and the quasi-governmental ZNPD. Most Zambians with mobility impairments, it can therefore be deduced, are stuck at home or in their home villages without adequate tools to move about. That my informants have had either the economic resources or social networks to acquire assistive devices – even suboptimal ones – is proof of their somewhat improved status.

3.3 Challenges, ethical questions and methodological considerations

My original intention with this Masters' thesis was to study assistive devices from a more phenomenological and medical anthropology perspective. This envisioned study would have focused on questions such as why people choose particular mobility aids over others, how they relate to their devices and so on. However, while in the field I started doubting my competence to delve into these questions sufficiently, at least in the available timeframe. Mainly this was due to naivety in the choice of topic on my part – though some interesting data were caught in the net – as discussed in Chapter 5 – it turns out users of assistive devices in Zambia mostly consider themselves lucky to have assistive devices at all, and as such they don't tend to be picky. Very few informants had the resources to truly consider anything besides availability, affordability and functionality when acquiring assistive devices.

On the phenomenological side, a likely issue was my suitability as a nondisabled person to study this topic. While I disagree with the notion that phenomenological studies may be conducted only by inhabiting the kind of body or undergoing the bodily experience studied (saying that we can only understand those who are like us seems to me to be the very antithesis of anthropology) it is clear that the endeavour is greatly aided by personal embodied experience, not least in the sense that it makes it easier for informants to

confide in the researcher. As such, three months in Lusaka quickly turned out to be far too short a time for me to make sufficient headway on such a topic.

Having realised this but being without an alternative theoretical framework, I continued to conduct interviews in largely the same, broadly biographical fashion throughout my stay in Lusaka, trusting enough things of interest would surface from the data this way. My interest in examining the technologies of the self employed by PWDs only began late in the autumn while sifting through my data back in Finland, as I noticed that such prescriptions for living a good life with a disability naturally came up in practically all of the interviews. While I am sorry that I did not have the opportunity to consciously pursue this topic on site, I hope that this choice of perspective will nonetheless be validated by the results of this work.

In this text, I have left the question of anonymity to my informants, with each deciding individually whether they appear on these pages under their real names or under pseudonyms. I have made this decision on the basis that, as I will demonstrate in this study, public appearances and the shunning of any notion of shame associated with disabilities are central aspects of the work of everyday ethical practice for many PWDs in Lusaka (see also Cole et al. 2011). Indeed, only one informant chose to go with a pseudonym. An exception to this principle are those informants employed in the medical or NGO fields, whose work might (by any slim chance) be influenced by the information given here, and whose identities I have therefore chosen to automatically obscure. Pseudonyms will be marked in the text by an asterisk (*).

All of my interactions with informants during fieldwork were conducted in English. While English is rarely the first language of Zambians, it is an official language and the language of all schooling from the second grade onward. English is also the language of government and the mass media. Especially in the big cities, then, the vast majority of the population are constantly exposed to and used to expressing themselves in English, despite the fact that, as Salminen (2006: 32) notes, "there is no 'standard Zambian English'". I do not therefore believe that my interview data has suffered in any reasonable amount due to my inability to find either the time or the learning resources to study either of the major Bantu languages in Lusaka, Bemba or Nyanja. (Indeed, other

anthropologists who have spent considerably longer periods in the Zambian cities have noted the difficulty of properly learning these languages, since English is so readily spoken; see Ferguson 1999: 18-19; Salminen 2006: 11-12.) My only major regret in this regard is missing out on some of the constant banter within groups like the Disacare employees and the basketball players.

My affiliation with Abilis while staying in Zambia had both upsides and downsides. Thanks to the Foundation's networks, I was able to establish some contacts from Finland during the preceding spring, a task which proved nigh-impossible with those institutions I didn't have Abilis contacts to. This allowed me at least one avenue to get "into the field" and start collecting data almost immediately on arrival, skipping a process that often takes considerable time when conducting fieldwork in a foreign setting – as was the case with finding a suitable clinic in this study. There was also a considerable reservoir of goodwill towards Abilis, which facilitated my making personal contacts among the persons involved in the projects.

On the other hand, the needs of Abilis did not always fully line up with the purposes of my research. Several of the organisations I visited concerned themselves primarily with populations not in the focus of this study, with many – such as APTERS – concentrating on issues concerning children with disabilities and their parents and/or disability types other than physical disabilities, such as intellectual disabilities and albinism. Therefore I spent much time at sites (and travelling to and from them) that I likely would not have chosen had I been fully committed to this thesis only. There was, however, a certain value to this as well, as it gave me a broader familiarity with the context of disabilities in Zambia in general. Conversations with parents at APTERS, for example, provided great insight into the financial and social troubles faced by those bringing up children with disabilities – valuable context for the childhood experiences of many of my informants.

It also needs to be considered what effect my affiliation with an aid-granting institution might have had on the data. The struggle for resources is, after all, almost omnipresent in the lives for most Zambians, and many of the project participants at least might have seen in me an opportunity to cultivate their prospects of receiving future funding. For

my part, I sought to make it very clear that I would have no say on funding decisions at Abilis, and that the Foundation was in any case not currently looking to fund new projects in Zambia. In my interviews, I made it a point to ask any overtly Abilis-related questions at the very end of the session, or during a different visit entirely, to avoid these questions from influencing the way informants answered my questions about their personal lives. While it is not inconceivable that some informants might have consciously or subconsciously presented a view of their lives that was geared toward, say, proving their economic responsibility or the positive influence of outside funding on their lives in order to prove their worthiness of assistance in the future, I would confidently estimate the risk of any drastic influence of that kind to be minimal.

In any case the effect of my being seen as a possible source of economic assistance due to my association with Abilis is likely to be small compared to the parallel effect of my being a white foreigner (*mzungu*) – an issue that I feel has been sufficiently discussed elsewhere (e.g. Cilliers et al. 2015; Halvorsen 2018). There is also the eternal and cross-cultural issue of informants telling the researcher what they think the interviewer wants to hear – a tendency which Salminen (2006: 11) found to be notably strong in Zambia, as was the avoidance of negative subjects. These are, however, unavoidable functions of any social research, unless we were to break the ethical (not Foucault-ethical) codes of research conduct, and conduct our studies in secret.

It is also important to note in this context that my specific focus in this study is not on the "objective truth" of disabilities in Zambia, but on the processes of self-formation by individuals with disabilities – processes that these interviews are themselves both a manifestation and a part of. Ugelvik, who studied the self-narration of prison inmates, puts it thus: "Appraising the 'truthfulness' of the accounts is not relevant in this perspective; rather, the focus is on understanding the dynamics of a specific kind of narrative and its social consequences, and on asking whether narratives of this kind in fact may be essential for people in general when they make sense of their own lives" (2012: 261).

Albeit that the informant might tailor their narrative to suit the researcher, in the act of narration they also (re)create themselves, making the narration itself a technology of the self. As Foucault himself wrote of self-writing:

> "[W]hen one writes one reads what one writes, just as in saying something one hears oneself saying it. The letter one writes acts, through the very action of writing, upon the one who addresses it, just as it acts through reading and rereading on the one who receives it." (Foucault 1994c: 214.)

4. The Situation in Zambia

4.1 A brief recent history of life in Zambia

Over the past century, Zambia's history – when viewed from the outside at least – has been defined by its spectacular economic trajectories. In the early 20th century, the commencement of massive copper mining in the Copperbelt province in the north of the country fuelled an incredible economic rise that reached its zenith around Zambian independence in 1964. In 1969 the country's GDP was not only one of the highest in Africa, but at the time topped countries such as Brazil, South Korea and Turkey (Ferguson 1999).

This economic ascension was associated with significant urbanisation, as Zambians flocked to the Copperbelt cities to look for wage-earning opportunities in the mines and the services that sprang up around them. These processes of economic development and urbanisation commanded Western interest in Zambia, both anthropological and otherwise, for many decades. Ferguson has noted how the external similarities of Zambia's economic rise to the Western Industrial Revolution – with its "noisy smelting plants and sooty miners" and "the smokestacks that dramatically appeared on the horizon" – fuelled the dogmatic view of Zambia as a frontrunner in the tale of "emerging Africa", an exemplary case of an inevitable modernisation that would see the continent moving towards familiar Western-style industrial modernity (Ferguson 1999).

This teleological process of modernisation was, however, dramatically cut short after the 1960s. The main factor for this was a precipitous drop in the buying power of copper, which alone accounted for almost the entirety of Zambia's exports. In but twenty years the economy sank, with per capita income slashed in half from 1974 through to 1994, and the state racking up massive debts. These debts forced the government to implement harsh austerity measures dictated by the IMF and the World Bank, which saw the quality of life for Zambia's urban population decline further. (Ferguson 1999.) In less than one generation, mineworkers, the raw muscle of Zambia's supposed modernisation, went

from buying mail-ordered suits from London and even owning cars to barely making enough to feed their families (ibid.: 12).

To add horrifying injury to economic insult, the HIV epidemic hit Zambia particularly hard in the beginning of the 90s. As a result of these factors, national health statistics also took a turn for the worse, with life expectancy at birth dropping from 52 to 47 years between 1980 and 1990, and infant mortality rates climbing from 99 to 123 per 1,000 births during the same period (Central Statistical Office 2000).

Under these bleak conditions, the urbanisation trend in Zambia began to reverse, as urban inhabitants began to re-evaluate their possibilities in the cities versus the countryside. While the growth of Zambia's cities has never stopped in the absolute sense, in 1990 the growth of Copperbelt cities was significantly lower than the growth rate of the national population. This trend of "counter-urbanisation" has been noted in other African countries undergoing periods of economic decline or stagnation (Ferguson 1999), and has significantly undercut the once taken-for-granted story of teleological development, though it must be noted that the decline of the Copperbelt population has not resulted solely from movement from cities to villages, but also from Copperbelt cities to Lusaka – the latter of which has overtaken the position of the former as the economic centre of the country (Salminen 2006).

Within the past decade-and-a-half, Zambia's economy has finally seen better years, with its GDP growth one of the fastest in the world, buoyed once again by rising copper prices (Central Intelligence Agency 2018). Corresponding improvement has been seen in other fields, with infant mortality figures halved from 1990 levels, and life expectancy finally surpassing the figures from 1980 in 2017 (Central Intelligence Agency 2018; Central Statistical Office 2000, 2012). Indeed, looking at most indicators of the Human Development Index (HDI), quality of life in Zambia has been on a slow but steady rise since the turn of the millennium (United Nations Development Programme [UNDP] 2016b). This growth continues to be precarious, however, since although the role of copper mining in the national economy has decreased somewhat, it still makes up 12% of Zambia's GDP and 70% of its exports (World Bank 2016), leaving the economy vulnerable to fluctuations in copper prices. Simultaneously, while Zambia's adherence

to punishing austerity programs bought it significant debt relief under the IMF/World Bank Heavily Indebted Poor Countries initiative, the national debt has continued to increase under the current government, more than doubling in size since 2011 (Commonwealth Secretariat 2018; QFM 2018). The future, then, remains uncertain.

4.2 Statistical view on disabilities

Turning to matters of disabilities specifically, the 2010 census found the national prevalence rate of disabilities in Zambia to be 2.0 percent (Central Statistical Office [CSO] 2012). As noted by the CSO itself, however, this figure should be taken with more than a grain of salt. Disability prevalence is notoriously hard to estimate, with the final result affected by the methods used in data collection as well as local factors. The WHO *World Report on Disability* specifically mentions the tendency of census methods – which are the most common methods used in national estimates in developing countries – to yield unrealistically low estimates on disability prevalence. Another big factor of course are the terminology and categories used in the data collection, as many of those experiencing such difficulties in daily life as to qualify them as "disabled" in the medical-sociological sense may not identify as such, leading many newer studies to focus on questions concerning "activity limitations". (WHO & World Bank 2011.)

The amount of categories included in censuses and surveys naturally influences outcomes as well. For example, albinism, regarded by most international actors as a disability in the African context, where it is often associated with serious problems for normal participation in society, is not measured alongside other disabilities in the 2010 census, but is instead devoted its own chapter (Central Statistical Office 2012). The Central Statistical Office has been steadily increasing the number of categories used in its censuses, however, and the jump in reported disabilities between 1990 and 2000 (from 0.9 to 2.7) no doubt reflects at least partially the incorporation of the categories "partially sighted" and "hard of hearing" alongside "blind" and "deaf/dumb" in the 2000 census. Yet the numbers remain conspicuously low.

Based on some of the most comprehensive studies from the early 2000s which utilised the activity limitations approach, the WHO estimated in the *World Report on Disability* that around 15% of the global population are living with disabilities, with individual countries moving in the 10-20% range, lower incomes corresponding with higher percentages (WHO & World Bank 2011). It is therefore reasonable to assume that the true prevalence of disabilities in Zambia falls somewhere within this range as well.

Regarding the CSO census figures with an appropriate level of scepticism, then, we can nonetheless use them to provide us with a rough image of disabilities in Zambia. Looking at the figures for prevalence of different types of disability (Table 2), two categories of impairment are clearly the most common: physical disability ("Any person with a physical abnormality relating to the loss of bodily limbs or any deformity in the bodily stature, e.g., the epileptics and leper."; 32.7%), and visual impairments (24.8% partially sighted and 4.6% blind, for a total of 29.4%). Hearing impairments, when counted together, also cross the 10% mark (hard of hearing 9.2%, deaf 2.5%, deaf/dumb 2.5%), while other types count for significantly less than 10% of disabilities reported – except for the "other disability" category, with 12.6%. (Central Statistical Office 2012.)

As for the causes of disability, disease was clearly the primary factor, accounting for over a third of cases. The fact that the second-most reported category was "unknown" (23.7%) likely reflects the scarcity of information on disabilities that is available to many Zambians, especially in the rural parts of the country – although this is only conjecture based on discussions with informants, as census data exists only on the province level, and provincial differences here are very small. Behind this, congenital causes, injury and other causes come in at rather similar levels (14.2%, 12.2% and 12.1% respectively), with less than 3% of disabilities caused by violence. (Central Statistical Office 2012.)

In my own data, informants usually estimated diseases and accidents on the road or at work to be the main causes for disability in Zambia, which based on my own observations might well hold true for those with physical disabilities. While polio may have been eradicated in Zambia some 20 years ago (Zambia Daily Mail 2015), its effects continue to account for a huge proportion of the physical impairments of Zambian adult PWDs. Traffic remains hazardous, with traffic accidents accounting for a few of my

TABLE 2.
Percentage distribution of population with disabilities by type of disability, Zambia 2010

Physically disabled	32,7	Speech impediment	3,8
Partially sighted	24,8	Mentally retarded	3,6
Other disability	12,6	Deaf/Dumb	2,5
Hard of hearing	9,2	Deaf	2,5
Mental illness	6,8	Dumb	1,9
Blind	4,6	Intellectual	1,1

Source: CSO 2012

TABLE 3.
Education and employment statistics, Zambia 2010

	Zambia total		Urban	
	Disabled	Non-disabled	Disabled	Non-disabled
Literacy rate (5 years and older)	58,6	70,4	74,3	84
Currently attending school (5 years and older)	16,6	34,6	19,8	38,8
Never attended school	34,4	20,9	20,7	9,3
Employed (12 years and older)	90,9	86,9	80,1	77,9

Source: CSO 2012

TABLE 4.
Percentage distribution of Usually Working Population (12 y and older) by Employment status, Zambia 2010

	Disabled	Non-disabled
Self-employed	52	44,1
Unpaid family workers	35,2	32,9
Paid employees	12,2	22,3
Employers	0,6	0,7

Source: CSO 2012

informants as well. A further cause less well represented among my interviewees but one I consistently ran into among older patients at the clinics was diabetes, which when left untreated can cause complications requiring amputation.

While I am not aware of any statistical evidence to back this speculation, I would think these last two causes might well be overrepresented among the relatively well-off PWD populace in Zambia from which my study largely draws, as their background factors and after-effects are emblematic of this group. Involvement in traffic accidents is made more likely by having the means to actively move around, while type 2 diabetes is often considered a lifestyle disease, given its association with sedentary work and a high-calorie diet, which in lower-income countries tend to be reserved for the comparatively wealthy (even though this too is starting to change on the global scale; see WHO & World Bank 2011: 33).

Despite the stigma still attached to disabilities in Zambia – discussed in the next section – the economic situation for the country's PWDs is not quite as bleak as might be expected – not in relation to the nondisabled population anyway. As is detailed in the WHO *World Report on Disability* (2011), relative poverty risk (poverty rate of working-age PWDs relative to that of working-age nondisabled people) varies from country to country independent of the countries' wealth, with a study of OECD countries finding almost double the risk in some countries, and only a slightly higher risk for PWDs than nondisabled persons in others. Likewise, in the so-called developing countries, household incomes are lower for households with PWDs than for those without in some countries, but equal in others and even higher in South Africa, due to the effect of disability grants. Zambia, according to the report, belongs to the middle category of equal incomes. (WHO & World Bank 2011.)

Census data on employment and education still reveal inequalities, however. School attendance and literacy rates, for example, are considerably lower for those with disabilities than for the general populace. While Zambia's socialist past has left the country with a far-reaching network of schools – travelling along the larger roads, at least, one gets the impression that even those clusters of houses too small to be rightly called villages won't be many miles from the closest elementary school – Zambia

nowadays is at the very bottom of the list of spending on education as a percentage of the GDP, ranked in place 170 out of 173 in the CIA Factbook, with even its closest neighbour on the list, the DRC, spending over double the portion (Central Intelligence Agency 2018). As a result, schooling is expensive, and many families struggle to send their children to school. In these conditions, my informants stated, many families view paying for the schooling of children with disabilities as "wasteful", preferring to focus resources on able-bodied offspring, who are considered more likely to see good returns for the investment. The results can be felt in the statistics in Table 3.

Employment rates, perhaps surprisingly, are actually higher for PWDs than the nondisabled (see Table 4): the 2010 census reports that 90.9 percent of working-age PWDs are employed, in contrast to 86.9 percent of their nondisabled peers. However, the nature of the employment attained by PWDs shows a clear disadvantage to the able-bodied. PWDs are significantly more likely to be self-employed or engaged in unpaid family work, i.e. working "without pay in an economic enterprise operated by a related family member of the same household", and less likely to be engaged in salaried work. This shows that PWDs are indeed disadvantaged on the labour market – though as the figures also show, the situation is hardly ideal for the majority of the population, regardless of disability status. (Central Statistical Office 2012.)

4.3 Encountered realities of PWDs

Besides the CSO data on disabilities, information on the lot of Zambian PWDs specifically is hard to come across. Studies on disability issues in the Global South have generally been carried out from the development perspective, which leaves data already limited in quantity yet more limited in scope. Among the many critiques of the development approach, Shaun Grech notes the incompatibility of persons with disabilities with the essentially neo-liberal agenda of development: "Development necessitates docile able bodies and minds to function and produce; the rest are to be corrected (cheaply) to function and produce, or removed – burdensome bodies on individualistic economies" (Grech 2016: 15). In striving for cost-effectiveness, Grech

argues, actors on the development field are tempted to focus on populations "easier" to pull out of poverty, and whose emergence from it comes with more readily identified and quantified results. (Grech 2016.) The PWD populace is thus easily overlooked, and when they are given attention, that attention tends to be on topics like improving functioning and participation in the workforce – certainly it is not on experiences of disability.

It is therefore good for the reader to bear in mind that the view on disabilities in Zambia and Lusaka specifically presented here is – outside of the 2000 and 2010 censuses – based on what I saw and heard from my informants in the field. Where possible, I have sought corroborating evidence from other sub-Saharan countries, but this is also not abundant.

Many factors contribute to the difficulties PWDs in Zambia face in attaining higher-status employment. The aforementioned lower education levels are of course one factor, though compounding this effect is the fact that even when well educated, qualifications held by PWDs tend to account for less than those of their nondisabled peers do. It is a well-noted fact in disability studies that socially, disability seems to define the person to the extent that it is all others see; incapability becomes the trait that is thought to permeate every facet of the PWDs existence. For example, an inability to walk might lead strangers (read here: potential employers) to assume one is also incapable of working as a typist, even though the two abilities are completely unrelated. The social psychologist Beatrice Wright termed this phenomenon *spread*, noting that in addition to physical capability, spread "involves social abilities and events as well. Others may look upon the person as less worthy, less acceptable" (Wright 1960, as cited in Sentumbwe 1995: 161-162). Negative beliefs surrounding disabilities of course do their part in making employers reluctant to hire PWDs as well.

Physical obstacles to economic equality are numerous. Outside of the city centre and the more prosperous neighbourhoods, Lusaka is still ruled by dirt roads, the uneven surfaces of which can hinder any user of mobility aids, and at their worst make passage nigh impossible, especially for wheelchair users. Even where roads are paved, actual constructed pedestrian walkways are far and wide between. This means either staying to the edge the tarmac, usually braving heavy traffic on narrow lanes, or navigating the

Figure 1. A regular road in Chunga, a suburb on the northern outskirts of Lusaka.

Figure 2. A road in Kabulonga, Lusaka, considered one of the wealthiest neighbourhoods in the country.

informal, stamped-out dirt paths beside them that are often intersected by ditches at every street corner. (See Figures 1 and 2). Even more official walkways might give way to such ditches, or else be separated from the car lanes by concrete blocks high enough and spaced in such a way that passing on and off the walkway would be a difficult feat in a wheelchair.

Adding to the difficulty, Lusaka has grown into a true metropolis, and sprawls across a considerable area – even more so since almost the entire city occupies the ground floor only. On the kinds of roads described above, it can be difficult enough to move a few blocks, not to mention moving from the outskirts to the city centre (simply called "Town" by locals), and sometimes right on through to the outskirts on the opposite side. This is what some of the players in the wheelchair basketball teams would do, coming in the morning from their homes in southern districts like Libala or Chawama to the OYDC next to the Heroes Stadium in the north – a distance of some 10 kilometres at the least, if measured in a straight line – and working their way back in the afternoon. For most mobility aid users, such a distance is quite impossible to manage, though interestingly this is one of the few situations where the wheelchair user is at an advantage compared to those with crutches, braces or prosthetics, which chafe and wear down faster – provided the wheelchair user can first get to a paved road and has the considerable constitution to propel themselves the whole journey.

Transportation, then, is a major issue, and for many PWDs a formidable obstacle. First, there is the simple issue of cost. While improving economic prospects have meant a considerable increase in the number of motor vehicles in Zambia, the total number in April 2017 was still estimated to be less than 600 000 (Njombo 2017), or one vehicle per some thirty residents. For most people, transportation thus means the public kind.

Public transportation in Lusaka consists of taxicabs – more or less official, but all quite out of the price range of most of those who cannot afford to own a car – and the fixed-route share taxi, known by many names in Africa (the most famous of which is perhaps *matatu*, in Kenya and Uganda) but ubiquitous across the continent. In Lusaka these were simply called minibuses, or just buses. A one-way ride from the suburbs to Town cost some 5-10 kwacha (around 0,5-1,0 euros in the summer of 2017) during my stay, which

was for many of the less well-off a substantial investment. Then, if one was headed to somewhere else than the very centre of the city, another bus would be required, as lines that circulate the city are practically non-existent. In addition, wheelchair users would often be charged double, as getting the chair in likely meant it taking up space that another passenger might have sat in.

If they could get in in the first place, that is. Climbing into the high and usually packed back compartment of the minibuses was reported to be a challenge by most prosthesis- or brace-using informants, not to mention the wheelchair users. For many, the only realistic option was to get into one of the two seats at the front with the driver. These were considered to be the best seats in the bus, and were usually the first ones to get filled, so PWDs in need of these seats would likely have to rely on the goodwill and/or understanding of either their fellow passengers or the driver to be granted them[3]. Wheelchair users would require extra goodwill from the driver or conductor for them to find a place for the wheelchair – goodwill that was often lacking, judging by the fact that a few wheelchair-using informants stated that when they were trying to catch a bus, half-empty vehicles would often zoom past without stopping. This despite the fact that most conductors seemed to me never to tire from loudly enticing potential passengers out of the bus windows.

Getting around was one thing, getting indoors another. While the majority of Lusaka's enterprise happens on the ground floor, this does not exclude plentiful steps, thresholds and narrow doorways that might block a PWDs way in. Most multi-storey houses in the city can be found in Town, many of which are government offices, and these will often be without elevators. Ramps, elevators and escalators are a feature found rather exclusively at the newer, fancier shopping malls.

The difficulties PWDs faced in moving from point A to point B within Lusaka was no doubt another contributing factor to their risks of economic marginalisation. To be able to go to work one must be able to *go* to work. Accessibility problems sometimes created

[3] One of the local companies operating the minibus lines had recently decreed that these front seats be reserved for passengers with disabilities. They only operated a limited number of routes in the city, however.

disadvantages in surprising ways: Moses, one of the founders of the self-employment project Action for Self-Reliant Disabled, told me that they had been forced to take out a loan on less favourable terms simply because they couldn't get into the bank offering the better terms! Jethro, an entrepreneur, reported similar difficulties in conducting business across Lusaka. Problems with accessibility affected a huge chunk of urban life, of course, not only economic activity but social life as well, and it was no wonder that these problems featured prominently in my interviews.

While older informants might remember having received comprehensive care, therapy and mobility aids education courtesy of government institutions in their childhood, after the structural reformation of the 1990s and early 2000s, obtaining any of these things has become more challenging. Treatment costs are high in comparison to incomes, and replacing assistive devices is an especially heavy drain on economic resources – indeed I admit to being surprised by how much maintenance was needed, despite having spent almost twenty years living with a wheelchair in the same household. Perhaps this is to some extent a result of lower-quality devices provided in third-world countries, but also the effect of a terrain that causes much more wear and tear, as discussed below.

Crutch and brace users got off lightly in terms of cost per repair/replacement, as these are relatively simple devices with only a few lightweight parts. For crutches especially, replacements are easy to obtain, as these are sold in most Zambian pharmacies. On the other hand, the need for repairs is considerably more frequent: the rubbers on the ends of crutches wear down in a matter of weeks in active use, and leaving them without replacement makes moving harder and risks damaging the crutch itself. Not that the frames of the crutches are eternal either, as supports and grips break or length adjustments become loose. Braces, meanwhile, can wear down quickly, and often require modifications due to changes in the user's height and weight. Both instances require the expertise of an orthopaedic technician.

Wheelchairs, in general, lost their usability very slowly and, when maintained properly, could last a very long time. This was especially true of the Disacare chairs that were designed for local conditions, with sturdy make and easy replacement of the parts that were most likely to wear down on the uneven roads. In fact, David Mukwasa, a Disacare

founding member and one of my interviewees, was still using the very first wheelchair produced by the collective. Usually, only air tires (in contrast to hard tires, which are meant to last the lifetime of the chair) required replacement, my informants estimated, from once per month at most to once per year at least, depending on the quality of the tires and activity of the user. Disacare models were designed to utilise bicycle tires, and this was not uncommon on other chairs either, meaning a cost of around 45-70 ZMW per tire.

Prostheses are arguably the most challenging mobility aids in terms of maintenance. While generally sturdier in make than braces, as relatively intricate and tailor-made creations they too can wear down in various ways that make use hard or uncomfortable, and once problems appear, the assistance of a trained technician is often necessary. This makes prostheses very costly to purchase and repair. A single basic prosthetic leg would cost hundreds of euros, or thousands in kwacha, and two of my more economically disadvantaged prosthesis-using informants used their prostheses for considerably longer than intended. For them, saving up for a new one was a years-long project, the success of which depended on their households experiencing no urgent economic crises, such as hospital trips.

Given that most users of mobility aids in Lusaka did not have the resources to keep their assistive devices in as good a condition as they might have liked – especially in such a challenging environment – device breakdowns were quite common among my informants regardless of the type of device used. Broken joints and serious chafing seemed to be the major problems faced by prosthesis and brace users; crutches would most commonly become loose at the length adjustment area (whether wearing down steadily or breaking suddenly); and wheelchairs might suffer a flat tire or – more seriously – a broken wheel bearing. An unprepared-for breakdown might then mean getting stuck in the house for days, weeks or even months in some cases.

Spares were the best solution to this problem, but their availability varied. Crutches were cheaply and widely enough available that their replacement was usually not too hard. While wheelchairs were maybe the most prone to problems requiring lengthy repairs, due to the relative longevity of the devices wheelchair users were also the most likely to

have a spare at home, usually an older model that was still somewhat usable. Previous models of braces or prosthetics, however, were rarely usable, whether due to wear or the user's changed body shape, as even small changes in height or weight might render them difficult to use.

Indeed, most of my informants, whichever mobility aids they were using, seemed constantly on the alert for possible opportunities to acquire assistive devices, and had often received such donations in the past from actors such as local churches and religious charities, as well as various NGOs (the Cheshire Homes Society of Zambia and the Zambia National Association of Persons with Physical Disabilities [ZNAPD] were particularly often cited examples). Most informants had strong ties to a particular institution and received assistance from them only, but several were involved with a few actors, keeping tabs on all at once. Iris*, a 24-year old veteran user of prosthetic legs gives an exemplary account of the importance of this resourcefulness:

> "I was lucky enough to be with parents who were exposed to… like who taught me at a young age how to be resourceful, so even if you know sometimes they would say government sponsorships, they'll help. But you go to government and they will tell you they are waiting for funds. And you need the leg, like, right there and then, and they tell you, 'oh, I'm sorry, we don't have the funds.' So you have to wait, and how long, you know, do you wait? So you now start improvising: as a person, can you use crutches, if not, what can you use in place of that? So, I always had that thing if I go to this place and they tell me to wait, I'll go to another place. I never like, I never had the patience to wait for those people, to come and… Which I would say helped me because if I was waiting I don't know where I would have been right now. I would have been a frustrated youth. (*laughs*)
>
> "– – Because I always had to think: Where am I going to find the money? Ok, my [leg's] loose, or it's in Lusaka and at that time I was in the north-western part of Zambia, I need transport to travel. Where am I going to stay? How much will that be, and… and I wasn't, I couldn't settle for a no, I had to go anywhere, wherever

> will help me first, that's how I was doing it. But other people waited. I even ended up finding them, I finished school and I found them waiting."[4]

Fellow PWDs were also a source of material assistance, and several had received used mobility aids from PWDs in their families or local communities. Almost all informants also mentioned a personal history of passing on, or an intention to pass on, their old mobility aids to other PWDs that were having to get by without assistive devices, after they themselves had grown out of them or they had the opportunity to switch to using newer ones (excluding of course the prosthetics users, these being of a far too individual make).

It is not only due to problems of accessibility, though, that life is difficult for those with disabilities. From the moment a person is born impaired or becomes impaired in Zambia, they become subject to a host of negative beliefs and baseless stories. As has been reported in various parts of Africa (e.g. Devlieger 1995 on Zaire, now the DRC; Katsui & Mojtahedi 2015 on Ethiopia), as well as other parts of the world (e.g. Nicolaisen 1995 on Borneo), in Zambia, too, impairments are often believed to be the result or moral shortcomings by either the person with disabilities or by their family members, most often mothers.

Having met parents of children with disabilities at a number of the projects I visited, I often heard first-hand experiences of the pressures mothers were subjected to after the birth of children with disabilities. Several recounted stories of relatives trying to persuade them to abandon the child, with one mother telling me how her husband and his family had wanted her to throw the baby in the river. How many parents cave in to these kinds of pressures, or go through with similar measures of their own accord, is hard to say.

Should the parents, or the mother in particular, refuse to abandon their child, they often find themselves ostracised by relatives. Most commonly, husbands would abandon

[4] The process of constantly monitoring assistive devices for breakdowns and looking for ways to acquire spares and replacements closely resembles the Mozambican concept of *dubriagem* analysed by Vigh (2011), and translated by him as *social navigation*. In social navigation, individuals in uncertain social and economic settings cannot make long term *strategies* but must constantly make *tactical* choices to get through the short-term, with little reference to incessantly shifting future prospects.

wives that had given birth to children with disabilities, leaving them with the child as well as any previous nondisabled children the couple might have. Rosemary, who ran an association for parents of children with cerebral palsy, told me she was lucky to have married that "one man in a thousand" that had stayed with her after their third child had been born with a disability. Other off-hand numbers given to me in conversation ranged from 80 to 99 percent of husbands leaving their families after the birth of children with disabilities.

Among those of my interviewees that had acquired disabilities in childhood, while there were several whose fathers had indeed left due to their disability, more fathers had stayed in the picture than this supposed 80-99% would suggest. This may, however, be a function – or rather a cause – of their representing a marginally more-well-off-than-average cross-section of the populace of the physically disabled. Still, several of them reported their disability as having been not only financially but also emotionally challenging for the family. Derrick, 37, who contracted polio at the age of two, gives an account that fits the archetypal progression of things:

> "For me… my mom's side, they supported me. Yeah, but with the side of my father, in fact unfortunately, because of me getting disabled, mom and dad divorced. Yeah. Dad couldn't hold it, say, 'how come you got a disabled child?' So, he couldn't live with my mom. So they went on separation and I went with my mom. So… the family of my mother knew who I was, but for my dad, it was very difficult to accept it."

In fact, while there are certainly physical obstacles to be surmounted for a person with a physical disability to move outside the house, the shame of having such a family member might equally lead many families to keep their PWD members behind closed doors and out of sight, even when they do not have the heart to completely abandon them. Even a well-meaning family may smother its PWD member with overprotection, thinking they keep the PWD from harm by letting them do hardly anything themselves (see Katsui & Mojtahedi 2015; Sentumbwe 1995). For PWDs to have control over their own lives, their families must first overcome this societally imposed shame or the desire to overprotect, or otherwise PWDs must eventually leave their families behind, whether of their own

volition or not. The latter was true of Seawell for example, who after his parents' deaths had lived in the rural town of Mumbwa with his maternal uncle, but was thrown out after losing his legs in a fire in his twenties.

There are also clear differences in the problems faced by PWDs of different genders. One of the standard questions in my interviews was whether informants thought life in Zambia was more difficult for PWD men or women. Interviewees regardless of gender nearly unanimously considered disabilities to be harder for women. This was mainly down to local gender roles, as women are largely expected to do the housework (cooking, fetching water, laundry, taking care of children etc.), much of which becomes difficult when physically impaired. Typical male jobs, meanwhile, involved increasingly more possibilities for intellectual work.

On the other hand, men were expected to provide for their families. Roland* – prosthetic leg user and father of three, as well as my one interviewee who considered life with impairments to be *a little bit* easier for women than for men (a few other male interviewees considered both genders equally disadvantaged) – used this as his argument: He reasoned that PWD women would be able to find companionship based on looks, but men, being disadvantaged to their able bodied peers in the labour market, would thus be disadvantaged in marriage as well.

Most others, however, suggested that while women might indeed find it easier to find "companionship", that was unlikely to translate into meaningful relationships. More abundant in my interviewees' opinion were able-bodied men who would, as Moses put it, "take them [PWD women] for a ride" and then leave them when convenient. This often meant women with disabilities finding themselves alone and saddled with children.

Census data would suggest that both views might in fact have some solid grounding. The data from 2010 show that, of the population with disabilities and over 15 years of age, significantly more men (53.3%) than women (36.9%) were currently married, although men were also more likely to never have been married (33.4% vs. 20.1%) (Central Statistical Office 2012: 75). I would take this to be evidence for Iris's* assertion

that "[a] guy, I think the only challenge would be if he's not working. But the moment he works, it's easy to find a lady because he's, he's settled."[5]

Women, on the other hand were twice as likely to have been divorced (7.7% vs. 3.6%) or separated (4.0% vs 2.4%). Despite Zambia being a patriarchal society, women with disabilities were also much more likely to be household heads (5.7% vs. 3.3%), which likely reflects the amount of PWD women left to raise children on their own. (Central Statistical Office 2012: 72, 75.)

[5] The critical nature of work for the eligibility of men in Africa for marriage, as well as the problems this prerequisite poses in today's economy, is well documented in anthropology. Hansen (2005) has written on this in Zambia; for other examples, see Masquelier (2005) on Niger; Stasik (2016) on Sierra Leone; Whitehouse (2016) on Mali and Honwana (2014) on Africa broadly.

5. Working on the Body

How did persons with physical disabilities in Lusaka seek to transform themselves and attain "happiness, purity, wisdom, perfection, or immortality" (Foucault 1994d: 225)? What were the technologies that they employed?

Much of the literature employing the concept of technologies of the self has been focused on physical transformations, whether that meant dieting (Chapman 1997), yoga (Sidnell 2017) or weightlifting (Wesely 2001), and Foucauldian theory has been widely discussed in sports studies in general (see Ashton-Shaeffer et al. 2001; Rail & Harvey 1995). When considering PWDs, however, one's first instinct might be that options for cultivating the body become rather limited when physically impaired. This has certainly often been the institutional view of the impaired body, which, unable to "get better", is beyond normalising discipline, and is better off shunted out of sight (Vehmas 2005: 56-59; see also Saraste 1996: 41-43).

This is, however, an example of *spread*, as most impairments leave the individual capable of a whole range of physical exercises, as best evinced by the rise of disability sports. Several scholars have indeed examined the sporting practices of persons with disabilities (Aston-Schaeffer et al. 2001; Guthrie & Castelnuovo 2001), and physical exercise also occupied a central place in my discussions with those informants who partook in wheelchair basketball or a variety of other sports.

Sports are only the most obvious form of such technologies of the self that take the physical body as their object, however. Manipulating aspects of physical appearance, such as clothing and conduct, has also been examined as a technology of the self (e.g. Roth-Gordon 2012; Valdez 2016). Compared to the able-bodied, persons with physical disabilities even have an additional aspect to their appearance to manage in the form of assistive devices. Besides contributing to appearance, assistive devices have further ramifications for sense of self and for mobility. This chapter examines some of the various ways PWDs in Zambia managed their physical presence in the world.

5.1 Assistive devices and "managing" disability

As stated in the third chapter, my original research question on the differing perceptions persons with physical disabilities held on mobility aids turned out to yield too few data for the purposes of a thesis. This does not mean, however, that I found no information on such perceptions. As it turned out, while most choices of assistive device were dictated by need and the scarcity of resources, differing attitudes towards different types of devices did exist.

Whether discussing my informants' personal preferences or the general differences between mobility aids, the theme of conspicuousness came up consistently. A certain order of preferability emerged, where (leg) prostheses occupied the top spot, since an artificial leg could simply be covered by a pant leg. Braces, of course, had a similar advantage, though none of my interviewees were (currently) able to go entirely without also utilising crutches or a cane.

When asked about the differences between different mobility aids, Roland*, 44, who had had one leg amputated at the age of 18 and spent many years on crutches before being able to acquire an artificial limb, touted the relatively inconspicuous nature of prosthetics as a definite advantage. Social life, according to him, was made considerably easier when his disability became less apparent. One could begin new relationships with a (relatively) blank slate, without having to overcome the stigma of disability first.

> "People assume, always, they underestimate you. And people believe a disabled person is someone who is meant always to beg. Of which is not fair. So, when at least you can put on an artificial leg, it's only those who are a little bit advanced, who can notice that… this guy is disabled. But most often the people just think that maybe you are just limping. Or maybe he's having just like a small problem with his leg, or maybemaybemaybe." – Roland*

This disability-obscuring potential of prosthetics would seem to correlate with what one of the technicians at UTH told me. She estimated that prosthesis patients at the clinic were much more often women than men, guessing this was due to greater image pressures on women. Of the four of my interviewees who were users of artificial limbs, only Roland* explicitly admitted to engaging in practices of obscuring his disability, but

of course, the prosthesis is usually fairly well concealed under a pant leg or the long *chitenge* skirt that is worn nearly everywhere by most Zambian women, such as my informant Mary. One female patient at UTH who dressed in more business-like attire managed to hide her prosthetic leg under a dark stocking so well that I had difficulty discerning which of her legs was artificial, and indeed she told me many would not believe she was an amputee until she had prompted them to touch the prosthesis. Most interestingly, Seawell, a 49-year old Disacare employee and para-athlete, was using a wheelchair to get around, but still sometimes wore his old, unusable leg prostheses under his trousers. Contrast, however, this quote from Iris*, born with a congenital disability and a prosthetic leg user from a young age, about her growing up:

> "I wasn't someone who used to cover my leg. I was… I was very fancy, I would say. (*laughs*) Yeah, that idea of hiding my leg wasn't something I grew up with. So, maybe when I wear a short skirt, maybe knee level – even my [school] uniform wasn't, when I was growing up, it was just to my knees so, yeah, that would like also draw a lot of attention."

While hiding disability completely might not have been a universally utilised practice, there seemed to be a general tendency to favour assistive devices that make one appear "less disabled". This factor also came up in comparisons between the two more visible mobility aids, crutches and wheelchairs. Richard, a 27-year old crutch user, similarly to many others, explained the difference between the two devices thus:

> "OK, I think their [nondisabled persons'] reasoning is like, when you are on a wheelchair, they consider you to be very weak, than using the crutches. So they would give more respect to the one using the crutches than the one using the wheelchair."

When I asked Moses, a 42-year old crutch user, about his aesthetic preferences for assistive devices, he even told me preferred muted colours on his crutches, as these were less visible from a distance. Brace and prosthesis users sometimes also noted a preference for darker hues that would be less noticeable against the skin. Most of my interviewees, though, considered colours a too trivial aspect to even be considered, and the few who did state some preferences (most of them women), more often framed this as a question of style.

While aesthetic differences were more often (if not always) presented in the form of 'other people's reasoning', one's own preferences between the types of mobility aids were almost always justified with differences in capabilities. More variance existed in these opinions, but still a large part of them seemed to conform to the preferential order of *prostheses/braces* > *crutches* > *wheelchairs*. There is certainly some truth to this conception of capacities – a wheelchair *does* limit access to more places than do prostheses or crutches, and crutches *do* take up the hands, while prostheses do not – but they also seemed often to spring from misapprehensions of what other PWDs could or could not do.

The limiting effects of wheelchairs, especially, appeared to me to be quite often overestimated by users of other devices. For example, Beatrice*, a crutch-user and lab technician, expressed gratitude that her father had insisted she learn to rely on a brace and crutches instead of a wheelchair, asking: "Sitting in a wheelchair, how could I have been able to work?" While I do not know the details of her job, imagining a wheelchair-using lab technician hardly seems a great stretch of the imagination. Likewise, Grace*, also a crutch-user and an officer at a disability-oriented NGO, had faced the same situation in her childhood as Beatrice*, and now asserted that wheelchair-users constantly needed someone to push or otherwise help them. This was, of course, patently not true: while some wheelchair-users may have conditions that do not allow them to propel themselves (and the more effortless electric wheelchairs are extremely rare in Zambia), this is not a function of the chair itself, and all of my wheelchair-using interviewees were able to move themselves deftly. Several interviewees also stated that sitting in a wheelchair one becomes "weak"– neglecting the fact that this is of course not inherent to the wheelchair, either, but a question of exercise.

PWDs themselves therefore seem to have internalised to some extent the prevailing view that sees different mobility aids as directly reflecting differing degrees of incapability. David, the founding member of Disacare, noted:

> "Unfortunately even some of the persons with disabilities (who walk) on crutches, even if he knows he's struggling to walk, especially long distances, still won't use a wheelchair. Because the wheelchair makes you look more disabled, more… like a patient, as [Kenny] said."

While none of my informants reported making such decisions themselves, some suggested that some of their peers, such as those who made their living by begging, might also choose their assistive devices with a mind to exploit these dominant conceptions and look more rather than less disabled. In the same interview with David, Kenny, the current Disacare executive, told me: "If you want people to have pity on you, then you don't show that ability. But if you show your ability, then people will consider you like any other person." This view was shared by Dr. Felix Silwimba, former Director General of the Zambia Agency for Persons with Disabilities and lecturer at the University of Lusaka, who stated that PWDs depending on begging often believe having a prosthesis would make them seem less needy. Others, meanwhile, would prioritise looking "more employable" with a prosthesis. (Felix Silwimba, personal communication, 27 June, 2017).

In her ethnography of hip-hop consuming Brazilian youth, Jennifer Roth-Gordon (2012) suggests that Brazilians of African descent use a variety of technologies of the self in order to "manage" their racial appearance. According to the context, they may employ means of attire, speech or body language to appear either more or less "black". In a similar fashion, I would argue, Zambian persons with physical disabilities may manage their disability through their choice of assistive devices and their possible concealment. Guthrie and Castelnuovo (2001) also documented technologies that PWDs in the US used to manage disability, separating from their data three different approaches to the task. The kind of image-shaping that I discuss here most resembles their category of "management by normalizing the body" (ibid.: 13-14); attempting to mould one's physical form closer to dominant ideals – which in this case meant either the ideal "normal" or the ideal "Disabled", according to personal and contextual needs.

Still, practical concerns usually won out over appearances, eventually at least. Beatrice* had gone without a crutch (that is to say, with brace only) for a long time, until a brother who worked in the medical field convinced her that she was undermining her mobility in the long run by forgoing a crutch. Derrick, 35, noted that as he got older, he too would eventually need the easier mobility of a wheelchair as age made his use of two crutches too taxing. And while Seawell, the para-athlete, stated he would go back to using prosthetic legs instead of a wheelchair if he could, it was his weightlifting hobby that

had originally made his upper body too heavy for prosthetics to support. Yet he had no intention of quitting or toning down his weightlifting, attesting to the greater importance of his bodily capability. Likewise, Mary, a 35-year old arm and leg amputee, had turned down her chance to acquire a prosthetic hand free of charge, as she felt she was able to do more with just her stump.

5.2 Relating to assistive devices

Another focus of my original research approach were the relationships persons with physical impairments formed with their mobility aids. This phenomenological focus might seem divorced from the ultimate theoretical approach of this study, but as I will argue here, the relation to one's assistive device turned out to be the object – the ethical substance, in the Foucauldian sense (Foucault 1994b: 263-264) – of various practices.

The vast majority of my interviewees reported very close emotional connections to their assistive devices. Many told me they kept constant tabs on their devices even when they were not using them, and were very particular about who handled them, preferring to keep them close at all times. This even applied to all crutch users – who could usually manage to go some lengths without them – save for Beatrice*, who only related so deeply to her brace. Derrick, a crutch user, and David Miti, a wheelchair user, whom I interviewed together at their workplace, answered my question on their relationships to their devices thus:

> Derrick: "With me, whenever I am seated, I have to see my crutches near me. Yeah, even if I'm sleeping, I put my crutches between the headboard and me, my crutches (will be there). Every time I open my eyes, I just reach out to touch (*unint.*) Yeah, so it's very good relationship with me, it's almost like I have extra limbs…"
>
> – –
>
> David: "It has to be near me, always. Every movement, I have to use it. A slight movement, I have to be on the wheelchair. I have to… keep it safe. It's always near, part of my body (anyway)."

While the functional value of keeping assistive devices close and safeguarding their welfare was obvious, most comments – like those above – belied a deeper emotional connection to them than a purely instrumental one. When talking of breakdowns, several informants put such weight to their words as if they were talking of physical pain. Indeed, the idea of an assistive device being part of one's body was extremely common in the interviews. Here are a few more answers to the question of interviewees' relationships to their devices:

> "My crutches and I are one. We relate so well. Yes. They are in my blood. Yes. We are just one." – Richard

> "I love my wheelchair, *so much*. They [kids in the household] even know, they don't even play with it. I don't like children playing with my wheelchair. 'Cos those are my legs. If they get broken (and things), and then I'll suffer, it's me." – Harriet

> "[When the brace is broken,] I just feel like something is wrong, my mind is not… settled. That's why I say that it's kind of part of me. Like an arm, you know when you are not ok, how you feel – just the same way." – Beatrice*

> "It's part of my body. Without them, there's nothing that I can do. There's nothing. If they're at a distance, I suffer a lot of anguish. So for me they are part of me. I hope even when I die, even on the day of resurrection I should have them! (*laughs*) In my coffin, my casket, yeah." – Moses

This last quote by Moses is especially noteworthy, as his joking insistence that his crutches should follow him into the afterlife is a clear rebuttal of the idea that there is something "wrong" with his body, and that the crutches are an extraneous fix to this problem, which he should be glad to ditch. Moses's quip is reminiscent of those PWDs who, 'resurrected' in virtual worlds such as *Second Life*, still wish their avatars to portray their physical selves as closely as possible, impairments and assistive devices included (Bloustien & Wood 2016).

Many interviewees argued, firstly, that a close relationship with one's assistive devices was a critical part of a healthy self-image, but also that cultivating such a relationship required a lot of work, thus relating the task to a consciously practiced ethical self-care.

Much of this had to do with the fact that getting physically used to an assistive device often required a long process of accommodation. At first, things would feel off, and the urge give up (if getting one's first device) or to go back to the old mobility aids was strong – Iris*, with her prosthetic leg, advocated hiding away old models during the transition period, and Harriet, who had at different points in her life used both wheelchairs and crutches, told me that during her transitions, the sight of a new assistive device had made her feel "sick".

Iris*, who started our interview using the terminology of her profession as an orthopedic technician but quickly slid into talking merely of her "leg" when referring to her own prosthesis, had an abundance to say on the topic. As noted before, her impairment was a congenitally short leg, which necessitated the use of a prosthesis. She had been given the option to have this leg amputated to improve her functionality with a prosthesis, but had chosen against it. Instead, she insisted that both her impaired leg – to which she had given a girl's name and consistently referred to it as a "her" – and her artificial leg were both crucial parts of herself. Being a fashionable woman, when going out Iris* would do the toenails on all three of her feet – "normal", short and artificial. She explained to me:

> "[For] a long time, when I climbed the bus, I used to say I have a problem. So one day I thought about it to say, [Iris*], you don't have a problem you have an artificial leg. And maybe you always think that's a problem, maybe that's why your leg thinks it's a problem, because it's our psychological effort. So I thought about it that day and I was like ok, so whenever I go on the bus, now I just tell them, 'guys, I have an artificial leg, I need to sit properly.' And that, I've seen, has helped me be more connected to my right side of myself, so yeah. And sometimes, like, yes, I know my leg is weak, but at times it's strong for me, like it just comes out for me, and I've learned to acknowledge that about my leg and appreciate. And I've seen that the more I appreciate my leg, then if, it's not growing back but I feel like it's becoming stronger because it's a part of me. So if I discard something that is part of me, it's more like I'm, you know, discarding myself on the way. - - We are a team, all of us. We accept each other the way we are. So I keep talking in plural, you can think I'm, like I have multiple personalities but yeah. (*laughs*) It's just how, helps to cope."

The assertion here is that the integration of an impairment into the self-image is not only psychologically healthy, but in fact strengthens the body too. Iris's* thoughts on her different legs also touch on the issue of acceptance, which we will examine at more length in the next chapter. In reference to the previous section, meanwhile, considering the incorporation of assistive devices into the self as a technology of the self provides us with a different way to interpret the motivations behind the preferences of users of prosthetics and orthotics for skin-like colours: Perhaps a visual similarity also facilitates an easier incorporation.

Noteworthy, though, is also the small but clear minority of my interviewees who did not view their assistive devices as an extension of the self. All of these interviewees were, for whatever reason, male wheelchair users, who instead described their chairs in purely instrumental terms as "tools" or "vehicles". Continuing the comparison to disabled players of *Second Life*, we might say that the views of these informants instead reflect the mentalities of players who do not carry their impairments or assistive devices over to their avatars, instead pursuing "a self beyond the limitations of physical embodiment" (Bloustien & Wood 2016: 101; see also Cole et al. 2011: 1175). This relates also to the management approach which Guthrie and Castelnuovo (2001: 10) called "minimising body significance – a concept that I examine in further detail in section 7.3.

5.3 Movement as ethical practice

The themes of mobility, movement and accessibility popped up in my interviews constantly. This is perhaps unsurprising when discussing mobility impairments, but it was the ontological value given to these themes that I found most striking.

There were, obviously, discussions on the instrumental values of personal mobility and environmental accessibility, such as keeping fit[6], being able to work and being able to shop around for the best deals, whether in groceries or – as mentioned in the previous chapter – in financing. These topics were nonetheless clearly overshadowed by

[6] Fitness was more often mentioned by wheelchair users, for whom upper-body strength was of the essence in ensuring movement, while brace and prosthesis users were more focused on weight watching in order to avoid putting too much pressure on their devices.

statements that emphasised the importance of spatial movement for very different reasons. On several occasions, the phrasing of my informants suggested that movement in space was seen to have an inherent beneficial value to self-development. This was particularly clear with Andrew, 28, the most recently impaired of my informants with seven years in a wheelchair, as he talked about the benefits of attending the basketball practices (to which he'd only started going a few months previously):

> "'[C]os you know, when you're just seated at home, again it's a problem. So at least if you can manage to be doing some activities, then your world will be always fresh. – – 'Cos if you say: 'Ah, me I can't manage to move out. Maybe I'm feeling shy, I can't move there and there…' No. If you can feel shy that means you can't do anything. At least if you can move up and down, that's when you can see things change. 'Cos if I can move here to another place, I'll get some other ideas."

To move, then, was in itself a tool for self-development. The importance of spatial mobility could also be inferred from the high value placed by informants on international travel. Informants who had travelled abroad were very keen to report on the extent of their journeys, and those who had not were happy to discuss their prospects and dreams for future travel.

Participation in disability sports especially had provided many informants with possibilities that would otherwise have been economically unattainable. This was particularly true for Seawell and Richard, who were both competing in para-athletics on an international level, but also for all the members of the basketball teams, who were, at the time, eagerly expecting the upcoming November trip to Harare to face the Zimbabwe national team. Work, NGO affiliation and education had also provided routes abroad for my informants.

Am I overanalysing the issue? It must be noted that travel is a topic that interests people the world over, and it justifiably might be asked whether it was not natural for it to come up so often, especially in the presence of a foreign researcher with clear international mobility. Many anthropologists have, however, argued that travel does hold a special place in the African imagination and that association with faraway places imparts the

traveller with a certain status benefit, and that has been the case for a long time (see e.g. Gondola 1999; Mains 2007; Ungruhe 2010).

Above all, movement was connected to values of self-determination. Expressions like "you have to do anything you feel like" (Seawell), "go wherever I want to go and see whatever I want to see" (Jethro), "go anywhere I want, when I want" (Beatrice*) were very common in the interview data. Explanations for the high value placed on autonomy tended to focus on the negative effects of not having it. In a clear analogue to the dangers of passivity mentioned in Western disability memoirs (e.g. Murphy 1990: 62-66), my interviewees shared the view that instead of testing and expanding one's capabilities, staying in the house and continuing to rely on others made one internalise the view that one could do nothing for themselves. Mary described PWDs stuck living with relatives as having a mind "like a baby". Instead of staying at home in the rural Western province, she had herself decided to move alone to Lusaka to "see her future". Living alone in the capital surviving on piecework was hard, but Mary preferred the occasional night on an empty stomach to living as a dependent.

Seeing dependency as a characteristic of childhood and youth while independence is considered a true criterion of social adulthood is common in Zambia (Hansen 2005), as it is in so many places across the world. It is thus no surprise that interviewees impaired at a young age described autonomous movement as becoming especially important during their youth. Recounting to me his short biography, Moses, who became disabled at the age of three and spent most of his childhood in a wheelchair, referred to an increased need for 'privacy' as the reason he chose to transition to using crutches (which he did without professional supervision):

> "[W]hen I became around 16, I didn't like the… When my mom picks me from school, she's able to lift me, put me in the bus, and… after- I didn't like that, I was a boy, growing up and I didn't like that, for me it felt very embarrassing. I forced myself to get back onto crutches."

Talking of her current life situation, meanwhile, Harriet told me: "You know what when you've grown, you need that independence, to live on your own, despite being disabled, we've got that (thing) of just being on your own." The slight increases in autonomy

offered by crutches in comparison to wheelchairs – one can reach higher, fit into a bus easier etc. – were in fact the most objective explanations of why crutches were preferable to wheelchairs, often coming from informants like Harriet and Moses who had prolonged experience of using both types of devices.

Another type of discourse on mobility incorporated human rights language to argue that spontaneous movement and autonomy should be enjoyed by PWDs equally to their able-bodied peers. Speaking of the need to be lifted into certain inaccessible public spaces, Grace* noted:

> "You know, I'm also a human being who deserves privacy. Ok, yes, when lifting maybe they can touch me anywhere, you know? I need also to be respected."

The human rights discourse might be understood in Foucauldian terms to constitute an alternative mode of subjectivation; PWDs must do things such as moving freely because that is their equal right as human beings. A Foucauldian analysis would therefore lend further credence to the benefits of the human rights approach that is currently popular in development work (see Katsui 2012). Derrick, talking about his hopes for the future of PWDs in Zambia, explained to me:

> "You see, in some areas, especially public places, there are few public places where I can find access to. So, and, you know, being human, we all think of going where other people may be found. So, with us also, we are part of those people, we are part of the government… So, all I can wish, is to have equal access."

As a last bit of data on the importance of movement and autonomy, I would like to present this rather long citation from Jethro. Discussing whether the government should provide PWDs with assistive devices, he nicely summarises many of the themes mentioned above, from the inherent value of movement to the right of self-determination:

> "You know, despite being disabled, people always should live our lives. We should do- we have got interests, we have got needs to meet, have you seen eh? We want to socialize like anybody else, have you seen eh? - - Because you know life is so interesting! Life is so interesting to live, it's very interesting because you can't just live your life and then you're just confined in a house just because you

> cannot move from point A to point B… You should be free also to explore the world!
>
> "You know me I believe in… I should not be a prisoner! (*laughs*) I should not be kept like a prisoner in that I'm confined (here; *unint*.) If I want to go out now, let me just get on my wheelchair; go out! Do whatever I want to do, come back and. You know, that's what makes life interesting. So, sometimes you know I feel bad if I see a person who is… The government should surely come in and help the people who cannot afford to get their mobility… aids for them to express themselves, (right,) to live a full life."

5.4 The question of help

Given the importance of autonomous movement, accepting help from others seemed to become a difficult issue for many PWDs. Wheelchair users were once more on the forefront of this problem, as I learned from my informants. All of my wheelchair-using interviewees reported receiving pushing assistance from strangers – usually without having asked for it. This kind of "help" often involved a stranger seeing a wheelchair user making their way out in public, and then grabbing the push handles and propelling the chair onward without as much as asking the PWD where they were going. Several informants stated such cases of assistance often ended when the helper reached wherever they were going anyway, and left the wheelchair there.

While wheelchair users recognised that this sort of behaviour at least originated from some level of charitable feeling, they also felt slighted by the way most potential helpers disregarded their capabilities and their right to self-determination. There is a clear parallel here to the Middle Ages European conception of PWDs as objects for the practice of virtue instead of fully-fledged subjects (Vehmas 2005: 41-44). There was an additional practical consideration to accepting help as well, since wheelchair users were worried that unaccustomed pushers would not understand to or be capable of avoiding any rocks, bumps or grooves in the road that might harm the wheelchair. For this reason, several of them told me they only accepted help from family members.

Other wheelchair users were more ambivalent about help. While he did not particularly want or need assistance, for example, Seawell opined that it was not appropriate to turn down help from strangers. Andrew, meanwhile, told me he liked to engage overenthusiastic helpers:

> "I say 'Hey, hold on first my guy! Where am I going, yeah? Check and ask first, that's when I can give you the right direction.'"

Unfortunately this kind of confrontation, or an appeal to mind the chair when pushing, would often be mistaken for rejection of help.

Economic help was obviously problematic as well, in as much as it limited the independence of those receiving it. As described in the previous section, Mary had felt living at her parental home to be too limiting, and left for Lusaka despite her family's deep concerns. Yet she told me that she did not turn down assistance from neighbours in her community – though at home, she would allow no one to help her with chores. All of my interviewees seemed completely fine with accepting assistance from NGO actors, which might be interpreted as a result of these relationships of help being less personal and posing less limitations on their beneficiaries (though Iris* did describe an attempt by some nuns to strong-arm her into taking the vows in return for a new prosthesis when hers was broken).

Grace* noted that the helpfulness of others, sometimes even the family, could often spring from what she felt was a "demeaning" unwillingness to believe persons with disabilities could do things for themselves:

> "In our language [Nyanja] they say, '*Aba beve sibazimvelela na chifundo*', that is in English they said, 'these people they don't even feel pity for themselves. Why is he doing this?'"

This kind of superficially positive attitude nonetheless does not include the possibility of viewing the PWD as an autonomous, mature person (see Katsui & Mojtahedi 2015). In order for PWDs to develop themselves, then, a central practice appeared to be the selective acceptance of help, and I will further consider some approaches to this in section 7.4 and Chapter 8. Meanwhile, Jethro made the importance of turning down help as a practiced technique most explicit:

Jethro: “You know that’s another thing. This is, other people think that you are not supposed to do what you are doing, other people will think that maybe they can do something to help you, so help is offered all the time. So you just have to learn which help you want.”

Eero: “How to turn down help that you don’t need?”

Jethro: “Yes, yes yes yes, that’s a *skill* which you have to… Sometimes you have to -Certain kinds of people will give you help, there are times in which you have to politely turn down the offer, that (I’m able to do what I will).” (Emphasis added.)

6. Working on the Narrative

As has hopefully become apparent to the reader, living with disabilities in Zambia is easy neither physically nor emotionally. Despite the best efforts of persons with disabilities as well as some clear legislative steps forward, progress toward accessibility is slow in Zambia – as it is all over the globe – and all the accessibility in the world is not going to allow a person with a disability to do everything that their nondisabled peers may do. An individual will always have to deal with the burden of capacities lost or never gained.

> "You know, there's a lot of things, eh, a disabled person is going through? Because, a disabled person, at times hates himself. – – A disabled person is someone who is suffering a lot… Suffering a lot, and having nobody to share his suffering with." – Roland*

Having obtained a degree of control over their bodies, whether through acquisition of mobility aids, exercise or slipping free of the overprotection imposed by family, PWDs are still faced with the challenge of controlling their image, their socially acknowledged personhood. As Roland* put it:

> "[Being] a disabled person, most oftenly what normally happens, people do not approach you to ask you your side of the story. People make up their own story. Yes. People make up their own story without asking you, what actually happened to you to find yourself in such a mess. (*unint*.) 'Ahh, that guy maybe was a thief', that guy maybe is this or is that, you get my point? Without *asking* you, what happened." (Informant's emphasis.)

In a similar vein, Iris* recounted of her school years:

> "It was a bit challenging to go to school. I used to run away from school, 'cos there were always funny stories about me: 'Oh, she got hit by a car', 'oh, she's the girl with three legs', stuff like that."

Humans form impressions on a variety of purely visual bases, before any linguistic clues come into play, and in the previous chapter, we have looked at some of the ways individuals with disabilities in Zambia might attempt to manage their appearances. The

fact is, however, that methods for influencing other people's impressions are comparatively limited for most PWDs, and moreover – thanks to the phenomenon of *spread* – the effects of such methods are often limited. Thus, of equal or even greater importance to PWDs' wellbeing are the technologies they use to shape disability discourse, both societal and internalised. In this chapter, I will examine some of the discursive technologies that surfaced in my data.

6.1 Acceptance

Perhaps the most common theme that came up in my interviews spontaneously, always without my guidance towards the issue as it was not part of my original research focus, was that of acceptance. In my interviews, accepting the self with impairments was often said to be the key to a good life with a disability, and almost without exception presented as the first step every PWD must take to stand any chance of happiness. Beatrice* reflected on her 36 years of living with a disability thus:

> "When I was little, when I started to have my conscience, I used to feel very bad. I used to feel bad in such a way that I used to put the whole blame on God. I said, 'Why is it that only me?' Those questions were going through my mind every time, [at] nine years, ten years, eleven years always, I was always thinking about it. And even at school if someone just said something to me, it used to hurt me very much. – – I can say that up to sixteen years, I was still thinking about it every (day.) I was just that anxious, I don't know, thinking a lot, a lot. – – So, until a certain time go by, I understood all things, and I understood what I was. I had to understand that, that the whole thing is not the appearance, that I see, it's just the inside that I am[7]. That's why, since that time I can say, things have changed and *I changed the way that I see things*. The way that I understand myself." (Emphasis added.)

This quote is a good example of the narratives of acceptance shared by many of my informants. Without exception, the path to acceptance is pictured as requiring a large amount of time and effort, whether one is born with an impairment or confronted with it at a later age. Acceptance always took years, and several informants across the

[7] Beatrice's* quote also exemplifies the sort of mind/body dualism inherent to disability 'management by minimising body significance' (Guthrie & Castelnuovo 2001) that is considered in Chapter 7.

spectrum of physical disabilities told me of having seriously considered suicide at some point before managing to accept their state. That a constructive acknowledgement of disability takes its time has been noted often in various types of disability literature (e.g. Guthrie & Castelnuovo 2001; Murphy 1990).

Beatrice's* quote is also exemplary in that in it, acceptance is not a sudden event that happens to the passive individual, but rather something that is achieved. Even more important, several informants stressed that acceptance was something that required constant work. As Roland* told me:

> "At times, you may feel bad, but you digest it, within yourself. And then that is the life of a disabled person. Each and every day, he must digest."

Iris*, as we saw in the previous chapter, felt that her sense of self had improved and her prosthesis strengthened by her ceasing to describe herself as having "a problem", and instead simply telling others she had an artificial leg. Here we can clearly note the way that describing oneself to others influences one's own self-image – "in saying something one hears oneself saying it", as Foucault said (1994c: 214).

Importantly, Iris* and Roland* both clearly framed acceptance as a matter of practice and not a state. This, too, rhymes well with Foucault, who stressed that ethical care of the self "is always a real activity and not just an attitude" (Foucault 1994c: 230). Given that I did not intentionally pursue the topic in my interviews, it is hard to say whether other informants' views of acceptance would have supported this – for example, Beatrice's* wording "I changed the way that I see things" might be interpreted either as an attitudinal break or as an alteration to practice.

Bodily techniques were also tied to the work of acceptance in various ways by the interviewees. Iris*, for example, associated the incorporation of assistive devices into the body with the acceptance of the self: "[H]ow am I just going to… accept myself if I just see [the prosthesis] as so, as just a tool or something?" Meanwhile, Andrew saw mobility as conductive to acceptance: "So to move around is very important again, 'cos if you just stay at home… I don't think you can accept things."

As stated above, acceptance was argued by many interviewees to be critical to success in life. In parallel fashion, denial of disabilities was viewed to be an obstacle, and, like Beatrice*, informants framed learning to accept their disability as a turning point in their lives that was often given even more weight than the acquisition of assistive devices (see also Saraste 1996: 38-40). While most informants considered the extreme poverty of some of their peers more of an outcome of various factors, several informants did go as far as to suggest a relationship between acceptance and success was mirrored by a direct relationship between denial and misfortune:

> "[T]he truth of the matter is, you will never lead a normal life, so you must accept all those challenges. And if you don't accept them, life will become very difficult with you, because you are going to be pretending to be somebody you are not. But if you accept who you truly are, it's very easy." – Roland*

> "[PWDs living off begging] are frustrated and they haven't accepted their situation. The most important thing is just acceptance, then you forge ahead." – Grace*

Acceptance was also seen as a prerequisite to sharing one's experiences with others, and thus preceded the task of spreading awareness of disabilities in society.

6.2 Being seen moving, being seen doing

Given that the dominant discourse in Zambia dictates that persons with disabilities stay behind closed doors, as discussed in the previous section, the simple act of moving outside of the house can be seen to constitute a transgressive practice. Movement is only half the transgression, though; the other, being seen moving. By and large, my informants were very aware that by being seen, they challenged perceptions of what PWDs can and will do.

As noted before, *spread* leads able-bodied persons to think that PWDs are by definition incapable, no matter the context. Demonstrations of capability thus challenged the effects of spread, which, again, my informants acknowledged. Iris*, for example, told me

of the time a boarding school she had applied to was about to turn her away despite her having the results to get in:

> "So I had like two meters before I could get admitted and I was about to be sent back home, 'til the head master just called me and asked me, 'do you want to stay here?' I was like, (*in a high-pitched voice*) 'yeah, I want to be in a boarding school, I want to be here!' And they told me, 'ok, people before you have left', but I told him: 'Those are others. This is me, you should give me a chance.' So they gave me a chance. – – And, it was because of my time there that they started accepting other people. Now other people started to come who were like me."

Even Grace*, who worked for a disability-focused NGO, felt that many of her co-workers were surprised she could do the things she did. Meanwhile, Jethro, who drives around a lot due to his work, recounted an incident with Tanzanian police:

> "I'll tell you one story. I was driving in Tanzania coming back here. This policeman stopped me when he saw that I was disabled, yeesh, he near arrested me. He says 'no, because you you are handicapped you're not supposed to drive.' I said 'ok, this is Africa'. So… what I did was to produce my driving license. My driving license entails me to drive in all SADC[8] countries. So I said 'ok, Tanzania is a member of the SADC countries isn't it? So, I'm allowed to drive here. If I can drive in Zambia I can also drive here.' So I've had a lot of such challenges."

The wheelchair basketball teams, training every Saturday at the OYDC, also recognized the fact that their playing constituted a presentation for nondisabled strangers gathered at the centre, and indeed, there always seemed to be half a dozen or more passers-by of all ages stopped by the edge of the court to admire the high-tempo game in bewilderment (see Figures 3 and 4).

The aforementioned examples present moving and doing solely as a challenge to the preconceptions of others; is this then more a technology of power than a technology of the self? I would bring up again Foucault's argument that the speaker hears themselves speaking and the writer reads what they are writing – similarly does the doer see themselves doing. I would therefore argue that moving and doing constitute

[8] Southern African Development Community

Figure 3. Derrick Tembo (centre) goes for the ball, David Miti (left) following behind. Photo courtesy of Viivi Mujunen.

Figure 4. Children gather to watch the game. Photo courtesy of Viivi Mujunen.

simultaneously both a technology of power and of the self. The division is, ultimately, more analytical than real, as Foucault insisted that his four types of technologies "hardly ever function separately" (Foucault 1994d: 225). The interplay of others' conceptions of you and your self-image was evident in this account by Beatrice* (who was handily transgressing conceptions of both disabilities and femininity through her activities):

> "Even my husband used to say that, say, 'you are, you are acting- you are not acting like a woman, you are acting like a man. You know that, when you decide something, you do it, and you have a strong mind. If you don't like something, you say you know, it has to happen like that.' So, and someone will say, 'you know, you can, you can lead easily.' And, that, I feel it in me. That is me."

Of course, the idea of empowerment through action is hardly new, and has been a core concept of development work like that undertaken by Abilis for some time (e.g. Sato 2016). Moses, as a founder of the Action for Self-Reliant Disabled group that had implemented an Abilis-funded income generation project, told me participants in the project had gained the "self-belief, that we can do something in a positive way", and several had indeed gone on to start their own agricultural ventures. Doing even countered the effects of spread on the self-image, as Andrew noted his engagement in wheelchair basketball had encouraged him to start dating again (see the very similar account by a young man in Ashton-Shaeffer et al. 2001: 109-110).

Besides changing discourse and improving one's self-image, moving around also created possibilities to engage with nondisabled strangers and challenge their preconceptions directly. This leads us nicely to the next technology in the arsenal of Zambian PWDs, sensitisation.

6.3 Sensitisation

Moving and doing may force others to question the assumptions they have of persons with disabilities, but it is an imprecise way of guiding discourse in a new direction. To really control representations of themselves, PWDs needed to engage more directly in the making of those representations, to actively push themselves and their stories to the fore in the place of rampant misconceptions (see Chapter 4). This is, of course, not so for

the nondisabled population, who rarely have the same kind of representational baggage thrust upon them (gender and ethnic stereotypes notwithstanding, at least in the case of Zambia).

The unequal distribution of the chance to tell their own stories was a topic that came up often, and seemed to deeply bother many of my informants. Indeed, many hoped that nondisabled others would ask about their impairments more often, which stands in stark contrast to what many Western PWDs think about the subject (see e.g. Webster 2016b). I suspect this is due to the differing dominant conceptions of disability: A moral approach still dominates discourse in Zambia, and this might make PWDs more willing to offer up the alternative explanatory model of medical science. Given that medical model of disability is already dominant in the West, meanwhile, PWDs can at least rest assured that they are unlikely to be seen as morally responsible for their impairments, and thus might feel like they have little to gain by explaining the precise functioning behind them (see also Vehmas 2005: 114-115 on the (ir)relevance of diagnoses to PWDs).

In development parlance, efforts to educate the general populace on disabilities (as well as other issues) are called *sensitisation*, and this term has found its way into the language of many of my informants – likely reflecting their high level of engagement with NGOs. For this reason, I have also adopted the term in this text to describe the active linguistic engagement of PWDs with others in order to change preconceptions of disabilities.

This kind of engagement requires a higher level of commitment and putting oneself on the line than many other practices examined in this study, and as such, it is understandable that sensitisation is not practiced all of the time and by everybody. Different contexts for fostering understanding of disabilities were recognised, however, and they seemed to be given varying degrees of importance, so that while constant sensitisation efforts were undertaken by but a few informants, many gave examples of *some* cases where they would attempt to influence attitudes towards PWDs.

There seemed to be an agreement that the closer the social circle to the person with disabilities, the more important it is that all persons within that circle be aware of and understand those disabilities. As such, sensitisation was at its most crucial within the household.

> "Us, even the family, you have to tell them the truth, you say 'This is my leg, and me I'm a Disabled, I'm not going to walk anymore." – Grace*

> "In your house, where you are living, your family, each and any one of them, to the last one, must be aware of your disability." – Roland*

In the next circle, where fostering understanding was still deemed to be highly important, were the people one interacted with on a regular basis, such as friends, colleagues and associates. A great example was once again offered by Roland*, who, as the strongest subscriber to the practice of obscuring disability, provided an interesting look into the contexts where he abandons that practice:

> "[W]hen you are into a prosthesis, those new friends you are going to make are the ones who are going to respect you. Because they won't know, that you are disabled maybe. Unless, after some time you may tell them: 'Gentlemen, look here, this is how I am.' And then among them you will see there will be some changes, eh? Some, who truly we are friends, will say 'OK, it's fine.' And those who were after something… they are going to… like walk away from you. Yes. It always have an impact. Always."

While he considered the obscuring of disability to have a positive effect on making acquaintances and moving about in the social world in general, he also implies here that it is important to educate close contacts on the condition of PWDs, and not worth it to associate too closely with those who are unable or unwilling to understand it. Apparently as a separate principle from the need for close relations to be informed, Roland* also stressed that any visitors to the house of an individual with a disability should also be made aware of that disability.

Children were considered an especially important target group for sensitisation, certainly due to their importance in the long term view, but perhaps also on account of a greater proportion of curiosity to learned avoidance. While Roland* recalled the hurtful nature of some of the attention given to him by children (he, like several of my informants, told of being described by children with the word "monster"), with them he also made exceptions to his usual practice of obscuring disability. Some of my informants such as Musola, who uses crutches, and David Mukwasa with his

wheelchair, who were otherwise very protective of their assistive devices, would still let children play around with them and try them out, in order to help make disabilities more mundane in their minds. Talking about letting others handle his wheelchair, David explained:

> "Children, yes, as you said it's part of education, also part of opening up, to them, so that they don't fear, because as a result of ignorance about disability – especially if you go out in the communities – you find that children, some, most children are afraid of a disabled person in a wheelchair, yeah. But they want to come closer, and once they get to use the wheelchair then you are good friends. Then they are all over, and you'll have the whole village pushing the wheelchair, you know, kids will be pushing you, yeah. For children I love to bring them closer, yeah, because once they get used to it then you are good friends."

Mingled with the fear and disdain many able-bodied feel for PWDs is an element of curiosity induced, firstly, by unfamiliarity with disabilities, but more strongly by a fascination with the technology of assistive devices. This curiosity can be seized upon by PWDs, whether dealing with young or old, to overcome the tendency for avoidance and to influence conceptions of PWDs.

Efforts to sensitise did not extend only to the nondisabled, but to other PWDs as well. Approaching strangers with disabilities seemed to be considerably easier, and as such was something that most of my informants would do, wherever such encounters happened. Of course, the sensitisation of fellow PWDs featured very prominently in the career paths of many informants, whether that be through traditional NGO activities (David Mukwasa, Moses, Musola and Richard) or engagement with patients/customers (David, Kenny and Iris*).

Spreading the word (Roland* literally referred to it as "preaching") on assistive devices was the most common goal of this activity, as knowledge of such an option was reportedly not widespread. Many informants were spurred on in these efforts by the vivid memories they had of the relief they had felt when they found out that there were other PWDs out there; that their conditions had a medical explanation (as this was often preceded by some level of self-blame); or that there were devices that might help them move around.

By "preaching" about assistive devices and sensitising in general, PWDs encourage newly impaired peers to move, to be seen and to sensitise in turn. Expanding the reach of a disability discourse stemming from PWDs themselves was seen as a crucial goal in changing the narratives on disabilities in the society at large.

6.4 Narratives of ability

I have frequently called back to Foucault's idea of correspondence as a technology of the self, and from this perspective perhaps the most interesting aspect of my data might not in fact be what my informants reportedly *did*, whether in regard to themselves or others, but what they *reported* doing. Though I examine broader autobiographical accounts than him, I follow here the lead of Thomas Ugelvik (2012), who examined the narrative technologies used by violent criminals in Norwegian prison when discussing the crimes they were accused of.

Discussing persons with disabilities in the same breath with criminals may seem somewhat tenuous, or worse, it might be taken as reinforcing some unwelcome associations – after all, too often throughout history have persons with disabilities of all kinds seen themselves lumped together with the "unwanted" of society (Foucault 1973: 39, 57-58; Vehmas 2005: 56-57). Whether deserved or not (and, just to be clear, it emphatically is not), PWDs do belong to the same broad category of "deviants" that normalising discourse finds problematic; a category which functions as a "contrasting agent" to define the "normal, decent, regular people" (Ugelvik 2012: 264). In classical anthropological terms, both criminals and PWDs represent "the Other". Similarities to Zambian PWDs in particular are made all the stronger by the prevalence of the moral explanatory model, meaning that, like convicts, PWDs are also suspected by many of being evildoers. As such, both groups face the challenge of narratively defusing their deviance and reconstituting themselves as ethical subjects, as legitimate parts of the body collective instead of problematic outsiders. Ugelvik (2012: 267) writes: "An analysis of moral self-making as part of everyday practice could concentrate on how people narratively make or talk themselves into being as ethically conscious or even ethically

superior people in a given socio-cultural context, and on how non-compliance is understood, explained and possibly sanctioned."

In narrative criminology this has been taken to entail techniques meant to "neutralise" crimes by way of, for example, denying responsibility, shifting blame onto victims or appealing to higher authorities (Ugelvik 2012: 260). In my data, the narrative self-making efforts of Zambian PWDs concentrated on portrayals of ability, directed at three points in particular: mobility, productivity and economic security. An additional layer of narrative construction emphasised the ubiquitous nature of disability as an issue that is not contained to a certain separate section of the population, but one that can affect anyone at any time.

As discussed in the previous chapter, the theme of mobility came up consistently throughout my interviews. Whether mobility was indeed pursued to the extent that informants talked about it, or if it was in fact the talking that was the foremost practice (or both equally important), it is clear that mobility gains an acute importance for those who can no longer take it for granted. In the self-narration of PWDs, their positive capacities for mobility were presented most prominently in the aforementioned tales of international travel, whether through participation in sport (Richard and Seawell), work and business (Grace*, Musola and Jethro, as well as some non-interviewee informants) or study (Iris* and Musola). It bears repeating that we might assume this to be a narrative technique not entirely unique to PWDs in Zambia, as the general status effect of international travel is well-documented not only in Africa (e.g. Gondola 1999; Ungruhe 2010) but also in other countries where travel is the domain of the relatively few (e.g. Lähteenaho 2016; Roth-Gordon 2012).

Related to the conceptions of PWD inability, induced by spread, there is an expectation that all PWDs are beggars or dependents – as Roland* put it, "people have made it look normal, for a disabled person to ask for assistance." This is one reason why people avoid those with disabilities. Given the economic hardships so many in the country find themselves in, any person with something to their name will be beholden to a large amount of requests for monetary assistance from various friends and relations, and avoiding the excessive piling up of these requests often occupies individuals' minds. As

such, they tend to seek out relationships with people in a better or equal economic situation, and avoid relationships with those of lesser resources. (See Ferguson 1999; Salminen 2006: 14-15.)

Countering this particular brand of stigma, many interviewees emphasised their financial independence, or the fact that others were actually dependent on them. Salminen wrote that the common Zambian expression for being financially secure is 'being safe', and that "as safety is both a sign of wealth and authority, people want to give an image of oneself of being safe" (Salminen 2006: 15). While I did not personally encounter this expression, I will take Salminen on his word, and we might for the lack of a better term call this theme of self-presentation *narratives of safety*.

Portrayals of capability were also one part of this narrative effort. This is, of course, a very broad topic, and the ways and the extent to which interviewees emphasised their capabilities naturally varied according to individual interests and personality. Grace*, for example, kept coming back to her academic and career successes, while Seawell detailed his athletic accomplishments at length. On a more general level, however, statements of equal – or even greater – capability to the able-bodied were very common. Andrew told me that the support of other PWDs in wheelchair basketball had made him realise "what an able-bodied can do, I also can do that," while in recounting his own struggle towards acceptance after losing his legs at the age of 34, David Miti concluded:

> "I still do the work… which the able-bodied can do. I'm still doing it. Maybe even more than those who are able-bodied, yeah."

When I asked Mary, who became impaired as a result of a traffic accident at the age of 12, whether she missed any activities from her life before her impairment, she simply replied: "I can't miss anything because I do everything." Meanwhile, Grace* acknowledged that, considering she was married, with a job and a house of her own, "some of the things I am doing other able-bodied even admire."

Many informants also described themselves as hard workers. Ashton-Shaeffer et al. (2001: 107-108) wrote that one of the important functions of sport for PWDs is as a field in which they can challenge and even beat the nondisabled. In the precarious economic environment of Zambia, I would argue, work can also function as a field of competition

where PWDs can resist preconceptions of inability, to a much greater extent than they could in the Global North. This is not to say that careers are not important for PWDs in the Global North – on the contrary (see Murphy 1990; Saraste 1996) – but achieving clear distinctions is less straightforward when the majority of the population is in formal employment.

A majority of informants – almost all of those who had established their own households, and even a few who hadn't – emphasised at some point in our interviews the fact that others were economically dependent on them, whether they meant the so-called nuclear family, or, equally often, siblings and their families. As noted before, having dependents is often one of the more crucial markers of full social adulthood (Hansen 2005; Honwana 2014). Derrick took the theme of providing for others to its broadest when talking of how the government should be able to provide assistive devices for its citizens:

> "Despite the kind of disability I'm having, but I can be able to make something to change the status of my living, to change the wellbeing of my family, and everything. Because, despite being disabled, I'm able to work on my own, I'm able to earn something, and *feed the nation*." (Emphasis added.)

Here Derrick moves up the different levels of care, starting from the self, and ultimately encompassing the entire populace among his dependents – surely a stark rebuttal to conceptualisations of being a needy outsider. Musola also told me that one of her aims in advocacy work was showing the general populace that "people with disabilities and other vulnerable people… can also create employment", and Iris* made a similar case when talking of the exact same topic, noting: "even I am offering something to society!"

Interviewees also regularly stressed the fact that impairments are unforeseeable, and may happen to anyone at any time. Most often this, too, came up in discussing why the government should do more to help persons with disabilities:

> "They don't even think about themselves. Because disability is not like you can ask for it, it comes at any time." – Harriet

> "Though it's a bad thing that there are accidents, but again, it's a good thing that there are accidents, people are losing their legs, and a lot of people are becoming amputated every year, so there'll come a point they'll see that there are so many

> people who need legs. So, it's a bad thing, but again, (*laughs*) it's moving towards that, you know that sensitisation. Maybe you find a minister who says you don't need a leg. He loses a leg to diabetes, he's going to see the importance of a leg and he's going to be our voice." – Iris*

In addition to acting as an argument for increased accessibility, I would argue that this kind of narrative device also works to question ideas of any fundamental difference between individuals with and without disabilities. Besides portraying themselves as mobile, productive and "safe" citizens, informants also sought to dispel ideas that they were in some way remarkable for having an impairment, bringing disabilities into the fold of the "normal". Analysing Myrphy's (1990) autobiography, Stronach and Allen noted a similar tendency – which they termed 'crippling the world' – to frame impairment as a universal human condition; "He may go before us, but it is certain that we will follow" (Stronach & Allen 1999: 41-42).

7. Practices of Freedom, Processes of Liberation?

Thus far I have focused on examining the different technologies of the self persons with physical impairments used to construct a more fulfilling relationship with themselves. To some extent, I have also examined their efforts to influence general conceptions of disabilities – efforts that, I have argued, simultaneously act to redefine their self-images. I have, however, avoided considering questions of whether these technologies constituted practices of freedom, and neither have I really considered the effects of these practices on broader systems of oppression. I have, in other words, mostly examined the kind of individualistic resistance that some scholars have criticised as inherent to Foucauldian theory, incapable of offering insights into the transformation of power relations in society.

To what extent, then, can we say that persons with physical disabilities in Lusaka undertook practices of freedom? And to what extent did these practices contribute to processes of liberation? With these questions in mind, let us re-examine some aspects of the technologies introduced in the previous chapters.

7.1 Practices of freedom and the presence of critical awareness

Being moderately successful, autonomous and active people, it is safe to conclude that my interviewees did not accept at face value the common conceptions of PWDs as being incapable of working, moving about independently, having families etc. Most of them did, however, describe themselves as having once internalised the passive and shame-filled role traditionally attributed to those with physical impairments, until through encounters with other PWDs or with medical professionals, or after an abundance of independent reflection, they began to question these ideas about themselves.

Valdez (2016) considered the access to alternative explanatory frameworks to be a key element in fostering critical reflection, and this did indeed seem to be the case in my data. My informants all had all been exposed to two or more modes of subjectivation, such as the traditional moralistic explanatory framework which placed the cause of impairment on the bad deeds of the individual or their family; the medical model

imported from Europe, which does not (usually) blame the individual but still sees the cause of disability as situated within them; and the human rights discourse influenced by the social model of disability, propagated mainly through NGOs and disability activism, but also ratified in Zambian law.

The confluence of multiple discourses may explain why, in my data, whether gathered in interviews or through observation, the medical field was so often presented as a positive force in the lives of Zambian PWDs, despite being a favoured bogeyman in both social disability studies and Foucauldian theory. Since in the West, medical discourse has been the dominant explanatory model for understanding disabilities – as well as the hegemonic mode of subjectivation for PWDs, for almost two centuries (Vehmas 2005: 56-59) – there has been a scarcity of "alternative conceptions of the good life" (Valdez 2016: 24) other than that offered by the field of biomedicine: living in a healthy, "normal" body.

In Zambia, the Western medical model has had comparatively little head start to the social model, and thus both have come to offer welcome alternative explanatory frameworks through which to contest the formerly dominant moralistic view. This awareness of multiple contesting discourses may also apply to nondisabled medical personnel in Zambia, giving them an increased capacity for critical reflection on disabilities as well. This would explain why my two interviewees working in the medical field, Beatrice* and Iris*, both felt so well accepted at their places of employment. Both expressed feeling that colleagues were more capable than the general population of looking past their impairments and treating them like anyone else. Experiences of medical personnel with disabilities in the West tend to be of the opposite kind (see Birkett 2003; Smith et al. 2016), though we may be seeing a shift happening in the field (see Blauwet 2017).

One might well argue that by complying to the old discourse on disability in Zambia, hiding at home and believing themselves incapable of independent life – let alone caring for others – PWDs would have a hard time attaining that "certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1994d: 225). There are few "coping mechanisms" (Markula 2003) that would help the individual with a disability to find

satisfaction in life while also internalising the common perception of disability as shameful and generally incapacitating. Technologies of the self being oriented towards the goal of personal satisfaction, then, in this context will require those employing them to already have gained the capability for critical reflection. Any technology of the self currently employed by PWDs in Zambia would, by that logic, count as a practice of freedom.

Taking this as our premise, my data would, at a glance, also seem to support the idea that an ethical care of the self leads individuals to engage in practices contributing to processes of liberation. Many informants had chosen their education or begun self-employment projects with the explicit intention of helping others like them. Those who had benefitted from engagement with sport attempted to entice others into it, as Seawell had done for Andrew. All seemed willing to sensitise, at least to other PWDs, and some had taken up more pronounced activism to influence policymakers; for example, Musola had gotten involved in the push for improved walkways in Livingstone town centre, and Harriet had taken part in a multi-storey stair-crawling stunt that got a government ministry to install elevators in its high-rise. Furthermore, all crutch or wheelchair users intended to pass on their devices to those without any upon acquiring new ones for themselves.

As I have tried to show in the previous chapters, however, the not all the technologies employed by my informants are entirely unproblematic in the "macro" sense. As Guthrie and Castelnuovo (2001) have noted, for example, attempts to normalise the body in an effort to make oneself appear "less disabled", while letting the individual feel more capable, do not seriously challenge oppressive norms on a societal level. Efforts to obscure disability hide the true numbers of PWDs in society, allowing the idea that disabilities are not "normal" to remain generally unquestioned, and as we saw, a feeling of personal capability did not discount some prosthesis or crutch users from underestimating the capabilities of wheelchair users. Nor did it necessarily prevent the physically impaired from underestimating those with other types of disabilities: "If you are mentally disabled… it's when, everything is over for you," as Roland* put it.

While disability scholars acknowledge the way disability discrimination is affected by the PWDs' membership in other marginalised groups (such as those of gender, ethnicity, sexuality etc.; Goodley & Swartz 2016), to my knowledge, few studies have examined the ways that the resistant practices of PWDs intersect with resistance to other dominant discourses (cf. McDonald et al. 2007). A slight exception has been the intersection of disability and femininity, which in turn has mostly been examined in relation to white women in the West (cf. Katsui & Mojtahedi 2015; Sentumbwe 1995). As noted in Chapter 2, the conclusions drawn from studies with this kind of focus have often been criticised as overly simplistic and universalising. Let us therefore examine two examples of ambivalent practices of freedom from my data, gender roles and association with other persons with disabilities, after which we will consider the questionable freedom involved in joking about disabilities.

7.2 Meeting the feminine ideal

The interaction of PWDs' attempts to contest disability discourse with gender relations has been noted to be a problematic area, as women with disabilities often attempt to attain a socially sanctioned but ultimately unequal form of womanhood. In the US, Guthrie and Castelnuovo (2001) looked at PWD women's sporting practice, and noted how much of it was oriented towards normalising the body by attempting to achieve the kind of feminine body ideal that was already fundamentally oppressive. In Ethiopia, meanwhile, Katsui and Mojtahedi (2015) looked at the efforts of women with disabilities to prove themselves capable around the house and prove their eligibility for marriage.

The intersection of gender and disabilities would was clearly of importance in Zambia as well. Certainly almost all interviewees, whether male or female, agreed that disability was harder on women in Zambia due to gendered expectations, but it remained unclear to me to what extent they questioned the validity of these expectations. In their narratives of ability, women would often emphasise their capabilities as housekeepers and mothers, while men rarely touched the subject of housework. This is not to say that my female interviewees did not also utilise narratives of ability from outside the setting

of the home – indeed, every one of them did – but that capability as a homemaker remained a largely accepted part of the self-worth of women with disabilities.

Katsui and Mojtahedi wrote of how many Ethiopian women with disabilities, being stuck at home, had to struggle against their families in order to be allowed the chance to demonstrate their abilities around the house. Wresting that control for themselves and showing family members as well as others that they could, for example, cook, thus became a highly empowering experience for them. (Katsui & Mojtahedi 2015; see also Sentumbwe 1995.) On the other hand, the authors noted that many PWD women and girls were kept rather more like domestic servants (Katsui & Mojtahedi 2015), which makes the pride of those women at fulfilling their household duties appear more like the coping mechanisms that technologies of the self have in some contexts been noted to be (e.g. Chapman 1997; Markula 2003).

The Ethiopian example demonstrates what Valdez wrote of practices of freedom: "the freedom involved in their practices is not determined by the content of the action undertaken (i.e., to unveil is inherently free, while veiling inherently unfree), but rather by the process involved in reaching the decision" (Valdez 2016: 23). Like veiling then, housework is neither inherently free nor unfree, but it functions as a practice of freedom when individuals use it reflexively, independently of the dominant discourses concerning themselves.

A few examples of the complexities of freedom concerning PWD and gender roles are in order. For one, in thanking her father for pushing her to move from wheelchair to armpit crutches, then to elbow crutches, Grace* did not criticise his reasoning:

> "I started with armpit crutches, but my father was still against that. He said 'you you are a woman and one day you are not- you are going to get married. But if you use those things how are you going to be carrying things?'"

On the other hand, the importance she placed on her housekeeping abilities had not ruled out Grace* getting a university education and rising quickly up the ranks of her employer NGO. Another non-interviewee informant was a proud housewife, but also ran an influential group of mothers of children with disabilities that *de facto* gathered at her house. Beatrice*, meanwhile, combined pride in her household capabilities with a

strong critique of gender relations. A Congolese immigrant, she had divorced her husband after he had come down with a drinking problem soon after their move to Lusaka five years ago. As we saw in section 6.2, she now took pride in her determination and leadership capabilities, which, as she reported, had made many consider her as possessing a somewhat masculine nature.

Ideals of female appearance came up comparatively very seldom in my data in relation to ideals of housekeeping and motherhood, possibly due to the relatively high median age of my informants. However, Iris's* practice of painting the nails of "all three" of her feet also exemplifies how a technology that is apparently oriented towards attainment of one discursive ideal (feminine beauty) can be used to contest other oppressive preconceptions (assistive devices as extraneous and unnatural) and build a better relationship with the self.

7.3 Being disabled – better together, or alone?

Whereas gender roles were (predictably) a much more discussed question with my female informants, another topic that often managed to liven up discussion regardless of the interviewee was the question of banding together with other PWDs. This was also one of the more contested topics in my data.

In a nutshell, my informants seemed to advocate or not advocate for greater PWD unity according to whether or not they themselves had partaken in PWD-only or PWD-majority activities, such as special schooling or disability sports. One of my regular interview questions – if the topic did not come up spontaneously – was to ask whether informants considered special or inclusive schools to be better for the PWD populace – a generally divisive question both within disability studies and without (Vehmas 2005: 105-107). Without exception, all interviewees considered the way they had been schooled the superior.

Those who had been to special schools themselves usually stressed the importance of seeing other PWDs for getting rid of their internalised passivity. Richard, who had spent only his first two years of schooling in a special institution, and Andrew, who became

impaired seven years ago at the age of 21 and was now in vocational training for PWDs, described the impact of special schooling in very similar terms:

> "It really helped me, because I… I never knew there were others out there. Yes. So it helped me to, to understand, say 'Oh, I'm not alone. There are others.' Yes. Despite not spending much of my time in special school." – Richard

> "I am doing this course in tailoring and designing. So after I reach that place, then I see a lot of people, you see, yeah a lot of Disabled, and I say 'Wow, this is good also. These are human beings just like me.' So I don't have to be like… feeling like (this … or what). I should just join these guys. So this is how I say 'ok, now I'm free.'" – Andrew

Other kinds of activities undertaken in the company of other PWDs had the same type of benefits. Informants who were active in wheelchair basketball described benefits like learning to question things that PWDs supposedly could not do, being able to temporarily "forget disability", and increased self-esteem in other areas of life. These views line up very strongly with the benefits of disability sports reported by Ashton-Shaeffer et al. (2001). David Mukwasa, who was one of the people involved in the original effort to establish wheelchair basketball in Lusaka, stated that its goals had been to "bring people closer" and help people "accept disability", thus tying the activity to acceptance as well.

Reasons to prefer inclusive schooling were more ambiguous, though they mostly resembled generally acknowledged arguments for inclusion, like the effect of special schooling to brand individuals as different from the general populace, strengthening the dichotomy of able-bodied/disabled (see Vehmas 2005: 102-103). My informants addressed this from the point of view of their personal development, as a fortunate circumstance in their lives, and not as a political statement. A somewhat different take, though, was offered by Iris*, who figured a normal school to be important training for a life where the PWD will not find "their kind" everywhere. As noted earlier, she also considered her stay in a normal boarding school to have opened the institution up for other PWDs to attend, in a way applying the principles of 'being seen' to schooling.

The most nuanced takes were perhaps offered by David Mukwasa and Harriet. David opined that special schools had been important in the time he had gone to school (around the 1980s), as they had introduced the broader population to the idea that PWDs were capable of going to school. Now, though, he considered them to have outlived their usefulness, except for those in need of special care. Harriet, meanwhile, took a very pragmatic and somewhat cynical approach to the issue. She considered the language of "inclusion" to be just a cover the government used to avoid having to actually improve services for PWDs, and therefore thought special schools to be a more policeable goal. This is a position akin to those in the Global North who see inclusive schooling as "morally and politically desirable, but – – often impossible to realise" (Vehmas 2005: 108).

Generally, it seemed that informants who had not been to special school were also less likely to see a need to associate with other PWDs. This did not mean that they avoided relationships with other PWDs, but that they did not see shared disability itself as grounds for engagement beyond any possible sensitisation. These individuals were unlikely to take part in PWD-only or PWD-majority activities, and none were participating in common activities like disabled people's organisations or disability sports. There is at least partial resemblance to the disability management strategy outlined by Guthrie and Castelnuovo they called "minimising body significance", where PWDs assume a sort of Cartesian mind/body dualism and emphasise the importance of the former while playing down the latter (Guthrie & Castelnuovo 2001: 10, 13). Roland*, for example, highlighted the importance of the mental side when speaking of how he disapproved of the way many PWDs turned to begging:

> "Such a person, despite the fact that I'm disabled, he *is* disabled. We cannot be friends. I want a disabled person who is able to do something for himself." (Informant's emphasis.)

While Guthrie and Castelnuovo (2001) focused on the liberatory effect of collective practice and the disability management approach they called "optimising mind-body functioning", however, my informants who more resembled the "minimising body significance" group still practiced power ethically through methods like sensitisation

and career choices. If we accept the postulations that engagement with contrasting discourses fosters the critical awareness that enables practices of freedom (Valdez 2016), and that ethical care of the self leads to ethical care of others (Markula 2004), we might ask whether these individuals had then perhaps been exposed to multiple discourses through other means? And indeed, it would seem that while those informants advocating common PWD spaces and activities often framed school or sports as their first exposure to something other than the objectifying moral and medical discourses, these informants framed the blooming of their critique towards an internalised passivity as the result of supportive but demanding parenting and/or years-long individual mental work.

To the informants of Katsui and Mojtahedi (2015) who were secluded in their homes, getting together and identifying with other PWDs was no doubt an unequivocally liberatory practice, whether we understand that through the lens of acquiring alternative understandings of themselves (Valdez 2016), or as an erosion of a state of domination limiting their practice of freedom (Foucault 1994a). Among my informants who were subject to a lesser degree of domination and had already acquired a capacity for critical awareness by other means, however, banding together with other PWDs was no longer seen so unambiguously and might have felt more like an unwanted obligation to put disability at the forefront of one's identity. This is the 'collective action becoming the new oppression' view that Guthrie and Castelnuovo (2001) resented, but which further drives Valdez's (2016) point that, from the individual's point of view, it is not the action taken but the processes behind it that matter.

7.4 Joking with disabilities

Lastly, let us examine the functioning of disability humour. While our interviews were certainly not deadly serious affairs, disability-centred humour made few appearances in them. No doubt, the context does not lend itself optimally to the use of this technique. Instead, this kind of humour came up more spontaneously during observation, as informants regularly made fun of their own or each other's disabilities.

Personnel at Disacare especially were fond of ribbing on each other's impairments, at least while I was around. One crutch-using employee who liked to wear a few more conspicuous personal ornaments was introduced to me by his co-workers as "the King of the Disabled", while my friend Charles, also a Disacare employee, jokingly taunted a regular customer who had come to get his wheelchair fixed, pointing at him and saying to me: "Look at this Disabled! He cannot even get out of the car!"

This kind of joking makes light of the sort of verbal abuse that persons with disabilities receive, but I would argue it also works to casts into question the importance that dominant discourse attaches to disabilities. The first joke plays on the idea that PWDs might be so a distinct a populace as to have a king, like a separate tribe, while the second seems to parody the idea that not being able to get out of one's vehicle is truly a noteworthy attribute.

The effects of parody and satire have been a topic of much discussion in the social sciences, and anthropology in particular. While anthropological classics examined humour as a mirror of the social whole, latter scholarship both within the discipline and outside it has instead focused on humour as a resistant practice (Petrović 2018: 204). Joking is often seen as fostering a sense of community within a marginalised group and articulating its common values. Parody is also understood – translated into Foucauldian lingo – as opening the way for critical awareness, offering "means of imagining a different moral order" (ibid.). As Albrecht writes of disability humour, it is important "in sum, -- because it points at the boundaries between cultural groups and at the social glue that holds them together" (Albrecht 1999: 67).

On the other hand, some recent scholars have questioned whether humour really is as subversive and emancipatory as has been suggested. They suggest that parody and satire make persons (or require them to be) "intimate with the targets of their critique" – perhaps to too great an extent (Petrović 2018: 210). Its targets become objects not of resistance but of "scoffing attraction, if not attachment", humour, "a socially acceptable painkiller that modifies the perception when the perceived situation cannot be changed" (Oushakine 2011, as cited in Petrović 2018: 210).

Yet many attest to the individually transformative power of humour. Of my informants, Harriet gave this some credence as she noted joking about disabilities one of the big upsides of the basketball practices. Stronach and Allan (1999) argue that through humour, as through a number of narrative technologies, persons with disabilities can effect a variety of transformations on their situation. Instead of being defined by their disability, through joking, PWDs themselves define disabilities as a joke, transforming them from passive victims to acting subjects; instead of reinforcing a taboo on acknowledging disability, they bring it to the centre-stage and normalise its presence in the social situation; they reclaim this aspect of their lives "for farce rather than tragedy" (ibid.: 34). Farce rather than tragedy might indeed be understood as another way that Charles framed his acquaintance's inability to exit his vehicle.

Musola used the alleviating effects of humour as a part of her practice of dealing with help, in order to soften her refusal to allow adult strangers to hand her her crutches, something she told me many regularly attempted:

> "So I usually joke with them when somebody rushes it, say 'How can you rush to pick my leg? Would I rush to pick your leg? You know, I'll tell you if I need help.' I'll joke. Then I'll also joke with them, 'Do you know what part of the leg you are… you are touching? So don't touch. Imagine if I come, what part of the leg you are- So (think about that).'"

Her use of humour reframes the situation, which might easily be interpreted as a discourteous refusal of help (as Seawell feared; see section 5.4), as a humorous event, and casts herself as an equal subject instead of an object of charity. Simultaneously, it acts to sensitise strangers on better conduct toward users of assistive devices.

If we were to accept Oushakine's postulation of humour as a social painkiller, disability humour would appear to be another technology of the self employed as a coping mechanism. But from Valdez's point of view, the fact that parody requires an intimacy with the object parodied by no means denies it a place as a practice of freedom. We might interpret this only as evidence of a former internalisation of that discourse, now called into question through alternative viewpoints (see Boland 2007: 115). This would make

disability humour a practice of freedom grounded in critical awareness, though the question of its place in the processes of liberation is left unclear.

To what extent can we really measure the effects of political humour on political action? Petrović, given the complex nature of parody and the difficulty of proving one thesis or the other as true exclusive of contradictory views, calls for anthropologists to shift away from the focus on the consequentiality of humour in light of a stark domination/resistance binary, and "toward ambivalent political subjectivities that unfold in the production and consumption of political parody" (Petrović 2018: 204).

From the feminist scholars criticising prior Foucauldian theorists for their lack of attention to the macro effects of individual practice to Petrović criticising the anthropology of parody for trying too hard to discern its societal effects while eschewing a focus on the individual level, it seems we've come full circle. Perhaps Petrović's prescription for dealing with parody would do for dealing with practices of freedom and their relationship to liberation as well: embrace ambiguity, for ambiguity, she suggests, is precisely as essential to anthropology as it is to real life (Petrović 2018).

Whether in regards to disability humour, to communal PWD activities or to the interaction of PWD and gender roles, the small sample size and broad approach of this study mean that these speculations must be treated as just that. The data do lend credence to many arguments raised by other researchers about the intersection of gender and disability, about inclusion and communal action, and about the power of parody, but above all, they draw attention to the complexity of freedom, empowerment and social change. Highlighted is also the ongoing need for more in-depth, ethnographic studies of PWDs centred on these complex topics of self-making and resistance to dominant discourses.

8. Conclusion

In this study I have hoped to present some of the technologies persons with physical impairments in Zambia use to, as Foucault, said, "attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1994d: 225). Of practices oriented toward the body, I have examined different ways of using and relating to assistive devices, the ontological value of mobility to those for whom it cannot be taken for granted, and the difficulties inherent in accepting help from strangers as well as family. Concerning the attempts of PWDs to control the stories of their lives both in their own minds as well as the minds of others, I have looked at the importance of accepting impairment, the power of being seen and the different spheres of disability sensitisation, as well as the various narrative routes PWDs take to "cast themselves as the protagonists and heroes in their own tales, as representatives of 'the good guys'" (Ugelvik 2012: 261).

Taking Valdez's understanding of practices of freedom, I have also argued that in order to pursue a satisfying life, persons with disabilities in Zambia *must* develop the kind of critical awareness required to call the prevailing moral understanding of disabilities into question. My informants being independent and relatively successful individuals, they apply this kind of critique towards dominant discourses on disabilities in their everyday self-making, thus marking these activities as practices of freedom. I have, however, also highlighted the fact that the same practices, while liberating in regards to dominant discourses on disabilities, might in some contexts be construed as reproducing other oppressive discourses concerning the individual, such as those of gender or a forced identification as disabled.

Several Foucauldian scholars have argued that resistant practices or practices of freedom are always highly contextual, with even a particular action having different effects on different levels. In her ethnography of Bedouin youth in Egypt, for example, Abu-Lughod (1990) argued that practices such as consuming Egyptian media and commodities functioned on the local level as resistance to the authority of tribal elders, but simultaneously embedded the Bedouin in global, capitalist power relations. While she may have left the question largely unexamined, Thorpe (2003), too, noted that in

their efforts to challenge the gendered nature of snowboarding media, her female New Zealand snowboarders contributed to strengthening ageist and ethnocentric images of the sport.

Such accounts show that in the mesh of societal power relations, it is hard to contest one dominant discourse without contributing to the strengthening of another. This grim-sounding outlook is no doubt what has caused more activist scholars like Guthrie and Castelnuovo to see Foucauldian formulations as unable to provide a path toward real, positive transformation. But it bears repeating also that Foucault's point was "not that everything is bad, but that everything is dangerous" (Foucault 1994b: 256) – one must, perhaps, be willing to accept a certain degree of imperfection or inconclusiveness to all liberatory pursuits, while simultaneously remaining convinced of their importance. As the man himself continued:

> "If everything is dangerous, then we always have something to do. So my position leads not to apathy but to a hyper- and pessimistic activism." (Foucault 1994b: 256.)

Given the complex nature of power and processes of liberation, perhaps a certain fault of activist research such as that of disability studies or gender studies is that the viewpoint easily constricts – to some extent, no doubt, due to practical constraints – to examine liberation as it pertains to the relevant group, whether it be persons with disabilities, women, ethnic minorities, sexual minorities etc. Often, then, the result is a text that ignores the way the efforts to improve the lot of one group may contribute to the marginalisation of another. This becomes especially grievous to people who belong to multiple marginalised groups, and/or do not feel that their membership in the group at the focus of research or activist efforts is one that is at the core of their own identities (Vehmas 2005: 144).

Besides the risk of ignoring alternative "forms of human flourishing" (Mahmood 2012, as cited in Valdez 2016: 24), a heavy-handedly activist approach, in my view, easily ends up sounding judgemental of those members of oppressed minorities who do not engage in acts of collective resistance. As anthropologists especially, if not as scholars generally, we must try to not pass judgement on people for not living their lives in the optimally

transformative fashion. After all, human lives are complex enough as it is – whether with disabilities or without.

On this topic, let us return to the question of help one last time. In Chapter 5, I argued that turning down pushing help constituted a technology of the self for wheelchair users, as they asserted place as active and autonomous subjects. David Mukwasa, however, looked at the issue from a different angle:

> "[S]ome persons with disabilities, especially wheelchair-users, most of them were… they'll not take kindly if someone just comes and wants to push the wheelchair, so (*unint*.), you know, 'I'm sorry, did I ask for help? (I can) manage you know.' Ended up getting shouted at, you know? Those are some of the comments I've gotten from people, whom I've… met for the first time, and to talk about, they say 'You know actually I, I've been looking at you and I thought can I help, but last time I did that I ended up being shouted at.' You know? (*laughs*) 'Who told you I need help? I don't need help, blah blah blah… But for me, I try to make friends, I try to bring people close, so that eventually they stop seeing the disability."

David looked at offers of help not as an event to address conceptions (outside or internalised) of PWD dependence, but to contest the prevailing moral view, which dictates that PWDs be nasty people. Given the way that such an approach might foster understanding of disabilities and help integrate PWDs into mainstream society, David may very well be right in asserting that this is a more efficient path toward social transformation.

The problem is, constantly evaluating of one's actions like this is incredibly taxing. Iris* - who could by no reasonable criteria be claimed to be guilty of enforcing states of domination of PWDs – explained the emotional toll of living life in such a fashion:

> "Because sometimes when we are different, we are tempted to be something that you are not. Like, I had occasions where I should just be nice, not because I want to be nice, but because… I don't know, I should be all angelic about what I am, so people should come to me and that has always been a struggle, to say, 'Why should I have to make people like me more? Why should I struggle hard to be acknowledged by people? Why can't I just be me, and people see me as me, and

> not have to be, you know, nice because – not that I'm a bad person, but I just have to be just me, you know? If I don't feel like being nice I shouldn't be forced to be nice. – – In a way you feel like you're not being you, you know? You live your life just trying to be the extra one who's open minded, the extra one who's nice…"

Iris* is not the only one to have noted this, as in the West as well, many PWDs have written of their resentment at a perceived obligation to keep up an approachable facade for the advancement of the disability cause (e.g. Murphy 1990: 107-108; Webster 2016a). The 8th edition of *Guidelines: How to Write and Report About People with Disabilities* specifically instructs readers: "Do not portray successful people with disabilities as heroic overachievers or long-suffering saints" (RTCIL 2013: 3). Academics, at the very least, should avoid adding to this baggage.

I acknowledge that in this text, I have myself made some decisions in order to improve readability that may look like heroic portrayals, or which alternatively risk making some of my arguments sound like criticisms of my informants, despite personal critique being the last thing I have wished to accomplish here. Simultaneously, I feel some would accuse the text of overt relativism in dealing with matters such as gender roles. Such is the difficulty in trying to portray both individual freedom and the larger processes its practice may contribute to. As with parody, as with processes of liberation, the writer must, perhaps, accept a certain degree of imperfection and inconclusiveness.

On the relationship of practices of freedom and processes of liberation, therefore, my conclusions remain ambiguous. Certainly it would seem that my informants, being practitioners of ethical self-care, did indeed exercise power ethically, as a large segment of Foucauldian literature would suggest – though the causal relationship was hardly straightforward. The size and breadth of this study are clearly not enough for claims of universal applicability, even on a national scale.

What is highlighted – and what will hopefully be a key takeaway of this text, like in so many preceding disability-focused texts – is that there continues to be a need for a deeper anthropological engagement with disabilities. The idea that disabilities are a social and cultural phenomenon as well as a biomedical one has begun to seep into policy objectives, but texts on PWD *subjectivity* remain hard to find outside of the genre of

memoirs – the vast majority of which come from the Global North. This is a gap that anthropology, with its deep ethnographic approach and global perspective, is well positioned to address.

Specific queries for future research raised by this study might include a deeper dive into the phenomenological worth of mobility for those for whom mobility is compromised, or a more focused look at the processes of relating to assistive devices. Examining technologies of the self employed among PWDs other than the physically impaired would also be fruitful grounds for comparative research. Persons with intellectual and multiple disabilities especially continue to be an underrepresented section of an otherwise already underrepresented population group (see Mietola et al. 2017). Not necessarily relating to the issue of disabilities, broader studies to determine whether indeed critical awareness leads via practices of freedom to an ethical practice of power might be warranted, given the standing implication in various texts borrowing from Foucault that this is the case.

Maintaining a cautious belief in the technological advancement of humanity, the complex field of impairments, the disabilities that come with them and the solutions to address them are certain to change shape in the future, both in Zambia and elsewhere. The phenomenon of disability, however, is unlikely to go away any time soon, and as has become ever clearer and clearer in the nearly four decades after the International Year of Disabled Persons, 1981, it directly concerns a vast portion of mankind. If persons with disabilities indeed make up some 15 percent of society as the *World Report on Disability* (WHO & World Bank 2011) claims, there is surely cause for disabilities to take up more of our time as social scientists. If that were not reason enough, then perhaps it will do to remark that – as many PWDs would remind us – disability concerns us all.

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